

**An Exploration of the Experiences of Community Integration
for Older Adults with Mental Health Issues**

By

Shannon Hebblethwaite

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ABSTRACT

An Exploration of the Experiences of Community Integration for Older Adults with Mental Health Issues

Community integration is vital for older adults with mental health issues, both as a process and as an outcome. The process of deinstitutionalization has made community integration a primary concern for these individuals. Many researchers recognize the significant lack of community resources that have been established in order to accommodate individuals with mental health issues in the community (Davidson, Hoge, Godleski, Rakfeldt, & Griffith, 1996; Pedlar, 1992). Researchers and practitioners alike, however, lack a thorough understanding of the factors that contribute to the successful and lasting community reintegration of older adults with mental health issues.

The purpose of this study was to provide an in-depth analysis of the experience of community integration for older adults with mental health issues. The study was guided by the conceptual framework of phenomenology, focusing on the lived experiences of these individuals (Patton, 2002). Utilizing qualitative methods, data collection consisted of semi-structured interviews, oral member checks and the maintenance of a reflexive journal. Participants in the study were five older adults who had been diagnosed with a psychiatric disorder, had received treatment on an inpatient geriatric psychiatry unit, and had returned to their homes in the community upon discharge from the hospital.

The findings suggest that being healthy and concomitantly maintaining independence played a key role in the process of community integration for these older adults. Independence, from the perspective of these individuals was quite different from the definitions of independence commonly used in North American society. The older adults in this study did not adhere to the principles of autonomy and individualism in relation to independence. Instead, they accepted a certain degree of dependence in order to prevent or avoid future disability, relapse, and readmission to hospital. A number of factors contributed to their independence, both positively and negatively, including: being healthy; social support; a smooth transition from hospital to community; maintaining feelings of self-worth; solitude; the power of knowledge; feelings of burden; and managing stress.

These findings point to an emerging model of community integration that incorporates the concepts of empowerment, recovery, inclusion, and independence. The experience of independence, as described by these individuals, evoked feelings of empowerment and was strongly associated with the concept of recovery. For these older adults, being healthy, and thus, independent, meant being integrated. The findings, as well as the process of conducting this research, have lead to a number of recommendations for future research and suggestions for practitioners and policy makers involved with these older adults.

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TABLE OF CONTENTS

CHAPTER 1: INTRODUCTION	1
1.1 Introduction.....	1
1.2 Significance.....	4
1.3 Purpose.....	7
CHAPTER 2: RELATED LITERATURE	11
2.1 Introduction.....	11
2.2 Older Adults and Mental Health.....	11
2.3 Deinstitutionalization.....	14
2.4 Community Integration.....	16
2.5 Constraints and Facilitators.....	24
2.6 Social Support.....	32
2.7 Leisure.....	34
CHAPTER 3: METHODS	38
3.1 Purpose.....	38
3.2 Research Questions.....	38
3.3 Guiding Conceptual Framework.....	41
3.4 Data Collection.....	43
3.5 Participants.....	45
3.6 Data Analysis.....	49
3.7 Trustworthiness.....	52
CHAPTER 4: FINDINGS	55
4.1 Introduction.....	55
4.2 Participants.....	55
4.3 Overview of the Findings.....	59
4.4 Independence.....	60
4.5 Stress: Before and After.....	63
4.6 Maintaining Feelings of Self-Worth.....	65
4.7 Solitude.....	66
4.8 Social Support.....	68
4.9 Burden.....	71
4.10 Being Healthy.....	73
4.11 The Power of Knowledge.....	75
4.12 Smooth Transition.....	77
4.13 Preliminary Conclusions.....	79

CHAPTER 5: DISCUSSION & SYNTHESIS.....	81
5.1 Introduction.....	81
5.2 Independence.....	82
5.3 Constraints and Facilitators.....	86
5.4 Recovery.....	95
5.5 Empowerment.....	97
5.6 Community Integration.....	100
5.7 Emerging Theory.....	102
CHAPTER 6: REFLECTIONS & CONCLUSIONS.....	105
6.1 Introduction.....	105
6.2 Reflections on the Research Process.....	105
6.3 Recommendations for Research.....	107
6.4 Recommendations for Practice.....	110
6.5 Final Words.....	112
References.....	114

List of Figures

Figure 1	Pyramid Model of Community Support.....	22
Figure 2	Hurricane Thinking.....	60
Figure 3	Bridging the Gap Between Dependence and Independence...	86
Figure 4	Pathways to Community Integration.....	104

Appendices

Appendix A	Interview Guide for Clients.....	125
Appendix B	Interview Guide for Caregivers.....	126
Appendix C	Letter of Information – Clients.....	127
Appendix D	Client Recruitment Script.....	131
Appendix E	Consent Form for Interview.....	132
Appendix F	Consent Form for Follow-Up Verification by Telephone and Permission to Contact Caregiver.....	134
Appendix G	Feedback Letter to Participants.....	136

CHAPTER 1: INTRODUCTION

1.1 Introduction

The benefits of leisure satisfaction to individuals' mental health have been well established (Caldwell & Gilbert, 1990; Hull, 1990; Iso-Ahola, 1994). Specifically, leisure plays an important role in the mental health of older adults (Mobily, 1992) and their caregivers (Doornbos, 2002). These two groups have particular needs and characteristics to which health professionals, including therapeutic recreationists, should be sensitive when planning and developing services with these individuals. When older adults are experiencing mental health issues, their relationships and connections with others become even more tenuous and challenging (Carling, 1995). It should be noted that for the purpose of this paper, the term "mental health issues" will be used to reflect any psychiatric disorders that have been formally diagnosed by a medical practitioner, including psychiatrists and general practitioners (family doctors).

Community integration is vital for older adults with mental health issues, both as a process and as an outcome. Carling (1995) states that all people have the right to community membership and participation. Despite this acknowledgement, many older adults with mental health issues do not achieve integration into their communities. They frequently report feelings of loneliness, boredom, and social isolation (Dugan & Kivett, 1994). Stigma (Goffman, 1963) has been found to be a major contributing factor to these feelings (Davidson, Hoge, Godleski, Rakfeldt, & Griffith, 1996).

Along with stigma, loneliness, isolation, and boredom, older adults with mental health issues experience a variety of constraints to community

participation (Pearlin & Skaff, 1995) as well as to their leisure participation (Mannell, 1994). These constraints are of an intrapersonal, interpersonal, and structural nature, and include issues such as lack of money, poor health, lack of time, ambivalence, and lack of supportive others. A significant body of research has examined constraints and the way in which individuals report and negotiate these constraints (Crawford, Jackson, & Godbey, 1991; Mannell & Zuzanek, 1991). Recently, however, theory has drawn attention to conditions that encourage leisure participation. Raymore (2002) refers to these conditions as facilitators. Although no specific research has been conducted examining facilitators for individuals with mental health issues, this idea is conceptually relevant to this population and provides some insight into the process of community integration.

Despite the constraints experienced by individuals with mental health issues, these individuals continue to adapt to their disability and find ways to participate in their communities. One factor that has repeatedly been found to play a key role in community integration for individuals with mental health issues is social support (Carling, 1995; Oliver, Huxley, Bridges, & Mohamad, 1996). The concept of social support is relevant to both the older adults, as well as their caregivers, and has a significant impact on the mental health and functioning of both groups.

Another major challenge faced by individuals with mental health issues is recidivism or multiple hospital readmissions. Relapse is a reality for many individuals and is often attributed to inadequate community resources (Fisher,

Geller, Altaffer, & Bennett, 1992; Frankin, Kittredge, & Thrasher, 1975).

Numerous researchers and advocates for individuals with mental health issues have suggested that deinstitutionalization has played a major role in the increased rates of recidivism (Appleby, Desai, Luchins, Gibbons, & Hedeker, 1993; Segal, Akutsu, & Watson, 2002). A substantial decrease in the number of hospital beds available and a concomitant decrease in the length of stay in hospital for individuals with mental health issues have had a significant impact on relapse and hospital readmissions in this population (Conn, 2002). In light of the challenge of remaining out of the hospital setting, a variety of conditions and interventions have been shown to decrease recidivism, including crisis intervention, aftercare, social support, and community integration (Gibson, 1999).

Efforts have been made to provide these types of supports within the community and to encourage leisure involvement for the growing older adult population (Langdon, Pearson, Stastny, & Thorning, 1989; MHA Village, 2000). It is believed that meaningful leisure involvement can contribute positively to the experience of community reintegration. Development of necessary community resources, unfortunately, has occurred at a much slower rate than deinstitutionalization. This has left individuals with mental health issues struggling to integrate into their communities. Researchers and practitioners alike lack a thorough understanding of the factors that contribute to the successful and lasting community reintegration of older adults with mental health issues. This study provides an in-depth analysis of the experience of

community integration for older adults with mental health issues. The findings provide policy makers and practitioners with suggestions for strategies to facilitate community integration for older adults with mental health issues.

1.2 Significance

Given the current budget restraints of both the federal and provincial governments, hospital stays for individuals with psychiatric disorders have become increasingly brief (Veltman, Cameron, & Stewart, 2002). These individuals are being discharged back into their communities at a rapid pace. The recidivism rate remains extremely high at approximately 75%, despite efforts to improve the supports within the community for these individuals (Bachrach, Goering, & Wasylenki, 1994; Gibson, 1999; Nelson, Lord, & Ochocka, 2001).

Older adults are a growing segment of the population. They represent individuals with diverse backgrounds who have specific needs and desires as they age. Mental health issues are a significant concern for older adults, with some prevalence estimates approximating 18-28% (Rosen, Pancake, & Rickards, 1995). These difficulties may occur early in life, or may have their onset in the later years, and are often related to significant life transitions such as the death of a spouse (Schneider, 1995). As well, the sudden increase in free time, often experienced in retirement, has the potential to create anxiety and confusion among older adults (Iso-Ahola, 1994).

The paucity of research related to older adults with mental health issues is noteworthy. Jeste, Naimark, Halpain, and Lindamer (1995) attribute this lack of research to a number of factors including insufficient funding and a societal

bias against aging individuals. They also report methodological challenges in research with older adults including the high prevalence of medical comorbidity, polypharmacy, and cognitive impairment among this population. These issues may easily confound research findings, making it difficult for researchers using experimental designs. Qualitative design, which invites participants to tell their “story” and recount their experiences, may be a more appropriate research approach for this population.

Leisure can play a significant role in the lives of individuals with mental health issues given its frequent association with feelings of independence, control, and a sense of belonging (Kelly & Godbey, 1992). The role of the Therapeutic Recreationist in the community integration process is an important one. Although this was of particular interest to me, this study did not focus solely on leisure and allowed the participants to describe any factors that they felt had contributed both positively and negatively to their experience with community integration. Literature related to community integration indicates that a variety of factors influence community integration. Leisure is just one of these factors. There has not been enough research conducted specifically with older adults with mental health issues to suggest that leisure warrants exclusive attention in this study.

Although leisure was not the sole focus here, knowing the potential that leisure has to improve quality of life was what inspired me to undertake this research. Having worked as a therapeutic recreationist on an inpatient geriatric psychiatry unit, I witnessed firsthand the frequent recidivism and the devastating

effects that this had on the self-esteem of the older adults. I heard the stories of the numerous challenges that these individuals faced trying to cope with a psychiatric disorder in the community. I needed to have a better understanding of what was going on in the community. Was there something more that we, as mental health practitioners, and therapeutic recreationists specifically, could be doing to promote successful community integration and decrease recidivism?

Despite the evidence of a revolving door syndrome (Conn, 2002), a constant pressure existed from the government to decrease length of stay in order to maintain current funding levels. The majority of resources continued to be allocated to institutional settings and community resources were inadequate to meet the diverse needs of older adults with mental health issues (Conn, 2002). In order to fully understand the needs of these older adults, we need to hear their stories. We need to understand what they perceive to be helpful in the process of community integration, as well as the barriers and constraints that they face, in order to structure health care resources to meet these needs.

A better understanding of the factors contributing to successful and lasting community reintegration has the potential for tremendous impact on the lives of individuals with mental health issues. A reduction in recidivism would have a positive impact on the quality of life of these individuals and would also provide substantial savings for the health care system. Researchers should endeavor to develop a more comprehensive understanding of the process of community integration and the services and supports that can facilitate this process.

1.3 Purpose

The purpose of this study was to develop an understanding of the experience of community integration for older adults with mental health issues. Older adults in this study included adults aged 55 and over. This age was chosen in relation to the admission criteria for the psychiatric unit used in this study. To facilitate a better understanding of the methods and findings, this unit is described in detail below. For the purpose of this study, community integration was examined as the participants made the transition from an inpatient psychiatric unit back into the community. “Successful” community integration was not defined by the researcher and was not a prerequisite for participation in the study. In accordance with the tenets of interpretive research, the participants’ meanings and perceptions of moving back into the community were used as the basis for understanding the process. Research questions used to guide the study will be discussed in Chapter 3.

The geriatric psychiatry unit used in this study treated individuals aged 55 years and over who had been diagnosed with a psychiatric disorder. This unit was part of a large geriatric centre in Southwestern Ontario whose mission was to enrich the quality of life of the elderly. This geriatric centre serviced approximately 3 000 older adults daily in a variety of programs and services, including:

- Geriatric Hospital – including:
 - Complex Continuing Care
 - Inpatient Psychiatry
 - Behavioural Neurology
 - Inpatient Rehabilitation
 - Acute Care

- Palliative Care
- Geriatric Assessment and Treatment Unit
- Home for the Aged
- Retirement Residence
- Group Living Residence
- Geriatric Day Hospital
- Psychiatry Day Hospital
- Geriatric Psychiatry Community Service
- Community Outreach
- Day Centre for Seniors
- Senior's Centre
- Outpatient Clinics

Of these services, those designed specifically to address the needs of older adults with mental health issues included the Inpatient Psychiatry Unit, the Psychiatry Day Hospital, the Geriatric Community Psychiatry Service, and the Geriatric Psychiatric Outpatient Clinic. The participants in this study had all been clients of the Inpatient Psychiatry Unit, one had used the Psychiatry Day Hospital, and four had been involved with the Geriatric Community Psychiatry Service. Each of these programs will be described below.

The Inpatient Psychiatry Unit was a 20 bed short-stay unit with an average length of stay of approximately three months. The unit serviced individuals aged 55 and older who received acute psychiatric treatment on the unit and did not remain on the unit for extended periods of time. The older adults were involved in programs and services provided by a multidisciplinary team including psychiatrists, nurses, a therapeutic recreationist, a social worker, an occupational therapist, and a dietician. Services were provided by physiotherapists, speech language pathologists, audiologists, and other specialists on a consultation basis.

After discharge from the Inpatient Psychiatry Unit, the older adults were encouraged to continue to be followed by a psychiatrist in the community. If the older adults did not have a psychiatrist in the community, they had the option of continuing on with one of the psychiatrists from the inpatient unit. If this was not preferred or not possible, they could be referred to a psychiatrist in the Geriatric Psychiatric Outpatient Clinic at the centre. If the older adults became involved with the Psychiatry Day Hospital or the Geriatric Community Psychiatry Service, as described below, they continued to be followed by the psychiatrists in those programs.

The Psychiatry Day Hospital was an outpatient service provided to older adults aged 65 years and older who had been diagnosed with a psychiatric disorder. This program operated on the same floor in the hospital on which the Inpatient Psychiatry Unit was located. Clients attended the program 3 ½ days per week from Monday to Thursday for a period of approximately 4 months. Programs and services were provided by a multidisciplinary team including: psychiatrists, nurses, a psychologist, a social worker, an occupational therapist, a dance movement therapist, and a dietician. Services were provided by physiotherapists, speech language pathologists, audiologists, and other specialists on a consultation basis.

The Geriatric Community Psychiatry Service was an outpatient service provided to older adults aged 65 years and older who had been diagnosed with a psychiatric disorder and were living in the community. This program provided support and follow-up care to clients on a regular basis from the following

disciplines, as needed: psychiatry, nursing, social work, and occupational therapy.

In summary, community integration is an important aspect of the transition for older adults as they move from inpatient psychiatric units back to the community. Community integration has been the focus of a significant body of literature in recent years. As well, a variety of factors have been shown in the literature to contribute to community integration, both positively and negatively. As a group, however, older adults with mental health issues have received little attention in the literature. The following chapter will provide an analysis of current research related to older adults with mental health issues, including the concepts of community, community integration, inclusion, deinstitutionalization, and constraints and facilitators to community integration.

CHAPTER 2: RELATED LITERATURE

2.1 Introduction

Community integration is an important aspect of the transition from inpatient psychiatric units back into the community. Literature related to the concepts of community and community integration will be reviewed in relation to older adults with mental health issues. The impact of community integration on caregivers will also be examined. Factors that have been shown in the literature to contribute to community integration, both positively and negatively, will be discussed. These factors include social support; leisure; deinstitutionalization; recidivism and relapse; and constraints and facilitators to integration including stigma, loneliness, boredom, and social isolation.

2.2 Older Adults and Mental Health

Older adults with mental health issues are a unique population within the mental health system. They have needs, desires, strengths, and abilities that are diverse yet they share a number of common characteristics. They are sometimes fortunate enough to be involved in supportive, caring relationships with friends or loved ones. These caregivers are faced with a variety of challenges but also experience a number of benefits from their relationships (Veltman et al., 2002). In order to fully understand the implications of community integration for these individuals, it is necessary to understand their characteristics and hear their stories.

Some researchers have been able to articulate the experiences of older adults with mental health issues. Older adults with mental health issues often report increased feelings of loneliness, boredom, and social isolation (Bridge &

Hutchison, 1988). They appear to be less extroverted than their younger counterparts and often report small social networks and a lack of social support (Lawton, 1994; McCormick & McGuire, 1996). Role-person misfit is common in older adults with disabilities whereby individuals possess feelings of incongruence with the roles that others have assigned to them (Pedlar, Dupuis, & Gilbert, 1996). These roles are often based on outdated images of older adults (Pedlar et al., 1996) and portray these individuals as severely disabled and unable to make positive contributions to society. The older person role emphasizes loss of competence, dependence, poverty, and a reduced ability to learn and change (Mahoney, 1994).

Despite the challenges of role-person misfit, some strategies have emerged to assist in ameliorating this situation. For example, leisure has been shown to facilitate the reclaiming of former role status by allowing individuals to demonstrate their strengths and abilities in a social setting where other individuals can more accurately perceive the role of individuals with disabilities (Pedlar et al., 1996). Social roles appear to play a major role in our society. In order for community integration to be successful, therefore, we need to be aware of the social roles that society has assigned to older adults with mental health issues and address the issue of role-person misfit for these individuals.

Although older adults with mental health issues face many challenges as they age, these individuals persevere and maintain many strengths and abilities. Lloyd (1991) found that older adults continue to strive to maintain a sense of control and independence. They are able to maintain feelings of mastery and

continue to be able to contribute to loving relationships with their families and friends (Pearlin & Skaff, 1995; Romsa, Bondy, & Blenman, 1985). Certainly, these individuals defy the traditional older person role with which society has labeled them.

Older adults with mental health issues benefit greatly from supportive relationships with friends and families, who play a significant role in the lives of their loved ones, often providing them with much needed emotional and instrumental support (Owens & Qualls, 2002). Family members often have multiple roles, including that of friends, landlords, and service providers (Carling, 1995). These caregivers are often the strongest advocates for the rights of individuals with mental health issues. They are important resources in the mental health system, as they are often able to provide a critically important perspective on the needs of individuals with mental health issues.

The role as a caregiver of an individual with mental health issues is not without challenges. Caregiver stress and burden are commonly reported in the literature related to older adults and mental health (Carling, 1995; Owens & Quall, 2002). This stress and burden remains even when the individual with the mental health issue is not living with the caregiver (Laidlaw, Coverdale, Falloon, & Kydd, 2002). Persistent stress and burden can have significant negative consequences for caregivers of older adults with mental health issues. Psychiatric disorders such as depression and anxiety are highly prevalent among caregivers, especially women (Wittmund, Wilms, Mory, & Angermeyer, 2002). Caregivers are frequently faced with feelings of isolation and blame (Carling,

1995) and often report a lack of support in their role (Doornbos, 2002). These challenges extend to all aspects of the caregivers' lives and have been found to affect employment, finances, parenting, and social relationships (Dore & Romans, 2001).

Notwithstanding the substantial issues faced by caregivers of older adults with mental health issues, these individuals have also demonstrated positive experiences in their relationships with their loved ones. Veltman et al. (2002) discovered feelings of gratification among caregivers of individuals with chronic mental illness. The love shared between these individuals and their caregivers remained strong. As well, the caregivers reported intense feelings of pride in the courage that they were exhibiting in coping with the challenges of caring for an individual with a mental health issue. These experiences reveal the strengths and abilities of the caregivers even under extreme duress. Such experiences should not be ignored by researchers in their examination of the caregiving relationship of older adults with mental health issues.

2.3 Deinstitutionalization

Deinstitutionalization has played a major role in the mental health system in Canada over the past three decades. Fundamental to this process has been the concept of normalization. The basic premise of deinstitutionalization and normalization is that all individuals have the right to live within their communities with the hopes of achieving autonomy, choice, freedom, dignity, and respect (Schneider, 2000; Wolfensberger, 1980). The deinstitutionalization

movement arose out of the exposure of poor living conditions in large institutions as well as the escalating costs of institutional care.

Although the concept is not new, community resources and services to accommodate this process have not been fully developed. Many researchers recognize the significant lack of community resources that have been established in order to accommodate individuals with mental health issues in the community (Davidson et al., 1996; Pedlar, 1992). Pedlar (1992) describes the fragmentation of community services, noting that the majority of community resources exist in the form of parents and voluntary charitable organizations. Despite the vast number of individuals with mental health issues who have been discharged back into the community, the majority of the health care funding remains in clinical facilities (Bachrach et al., 1994; Carling, 1995).

The lack of adequate community resources has led to the transinstitutionalization and/or reinstitutionalization of many individuals with mental health issues, especially older adults (Davidson et al., 1996). Instead of receiving treatment in psychiatric hospitals, many individuals have merely shifted their location, now receiving treatment on inpatient units in general hospitals. Many older adults have been moved to nursing homes and other long-term care facilities where they often receive very few specialized services designed to meet their mental health needs (Rosen et al., 1995).

Individuals with mental health issues have voiced their desire to receive mental health services within their communities with the hopes of achieving community integration (Davidson et al., 1996; Hastie & Pedlar, 1993; Mahon,

Bullock, Luken, & Martens, 1996). Recreation and leisure service providers, especially therapeutic recreationists can play a significant role in the social integration process of individuals with disabilities (Pedlar, 1990). Leisure has a substantial social component, which can facilitate meaningful relationships among community members.

The process of deinstitutionalization has had major consequences for older adults with mental health issues and their caregivers. It has left the older adults with inadequate community supports and has consequently placed a significant portion of the responsibility on their caregivers. Hospital readmissions have soared in relation to the decreased length of stays that older adults are experiencing (Appleby et al., 1993). Evaluation of the deinstitutionalization process has been inadequate (Pedlar, 1992) and further research is needed to determine the outcome of the process to date.

2.4 Community Integration

Before it is possible to understand the process of community integration, it is necessary to give a brief introduction to the concept of community.

Community has been defined and understood in many ways by numerous authors from a variety of disciplines. McKnight (1986) defines community as a social network made up of individuals, informal groups and associations where people co-operate and act through consent. Walter (1998) views community as inclusive, complex, and dynamic, consisting of the following key ingredients:

- shared vision;
- sense of purpose and values;
- wholeness incorporating diversity;
- caring, trust, teamwork, respect, and recognition;

- communication, participation, and affirmation;
- links beyond the community;
- development of new members;
- conflict resolution;
- investment in community; and
- community resources.

Community can be understood in a psychological sense, as a geographical concept, as a social network, or from an associational perspective (Hutchison & McGill, 1992). From a psychological viewpoint, community is a feeling of belonging and consists of common bonds and solidarity.

Geographically, community is a common space that people share in which they develop social contacts and feel a sense of place. The social network perspective consists of all of the people within an individual's life who provide information, resources, friendship, and/or support. From an associational perspective, community is derived from participation in activities with others who share a common interest (e.g., voluntary organizations, clubs, or informal community groups).

Community may be both positive and negative for individuals with mental health issues. Community can exemplify sharing and co-operation as indicated above. This, however, may not be the reality for many individuals. Not all communities are ready to welcome newcomers, especially those who possess characteristics that deviate from the social norm (Pedlar, 1996).

Community integration requires that the community be open to and accepting of individuals with disabilities (Pedlar, Haworth, Hutchison, Taylor, & Dunn, 1999). This openness does not exist in all communities and must become a

priority in order for individuals with disabilities to achieve community integration.

Despite the lack of a clear definition of community, it remains an important concept to many individuals, providing them with a sense of belonging and an opportunity to develop social networks and support. In conducting this study, I was sensitive to the aforementioned frameworks but will allow the participants to utilize and describe their own ideas and perceptions of community.

Much of the recent literature related to community integration points to the importance of normalization and social roles and relationships for individuals with disabilities. Although a significant portion of the literature focuses on the physical aspects of integration such as housing for individuals with disabilities, many authors acknowledge that social integration and inclusion are paramount to the process of community integration. Some key principles of community integration are outlined in the literature as follows:

- All people, regardless of any differences, belong in a community;
- People with differences can be integrated into typical neighbourhoods, work situations, and community social situations;
- Support is necessary for all people and their families; this support should be offered in regular places in the community, not in specialized settings designed for people who are “different”;
- The development of relationships between people with and without labels is crucial;
- People with and without labels have much to learn from each other;
- Service users and their families should be involved in the design, operation, and monitoring of all services, and should have the power to hold services accountable (Carling, 1995, p. 15-16).

Some researchers have described community integration as synonymous with community living and inclusion, conceptualizing it as participation and contribution in every aspect of community life (Townsend & Ryan, 1991). Broader definitions of community integration have addressed the issues of age-gender-culture appropriate roles and emphasized the importance of relationships and the natural community setting (Lee, McCormick, & Austin, 2001).

The community integration movement, as intimated above, has been driven to a considerable degree by the principle of normalization. Normalization has been defined as the “use of culturally normative means to offer persons life conditions at least as good as that of average citizens, and to as much as possible enhance or support their behaviour, appearances, experiences, status, and reputation” (Wolfensberger, 1980, p. 8). This principle has been recognized by both researchers and participants alike. Individuals with mental health issues have indicated that they had a strong desire for normalization (Hastie & Pedlar, 1993). Hastie and Pedlar (1993) found that individuals wanted to be able to participate in regular opportunities in the community without being labeled according to their disability. Similarly, Mahon et al. (1996) found that adults with mental health issues preferred to receive their leisure education in the community rather than in a segregated setting in order to normalize the experience. The concept of normalization has influenced the development of social role theory (Wolfensberger, 2000). Social role theorists posit that individuals’ life courses are characterized by a number of role transitions and adjustments to life events (Horna, 1994). These events and

adjustments influence individuals' perceptions of themselves and others. The social roles attributed to individuals through this process are thought to have a major impact on how individuals behave and treat others (Wolfensberger, 2000). Individuals with disabilities are often treated negatively by others because their social role is devalued by able-bodied individuals.

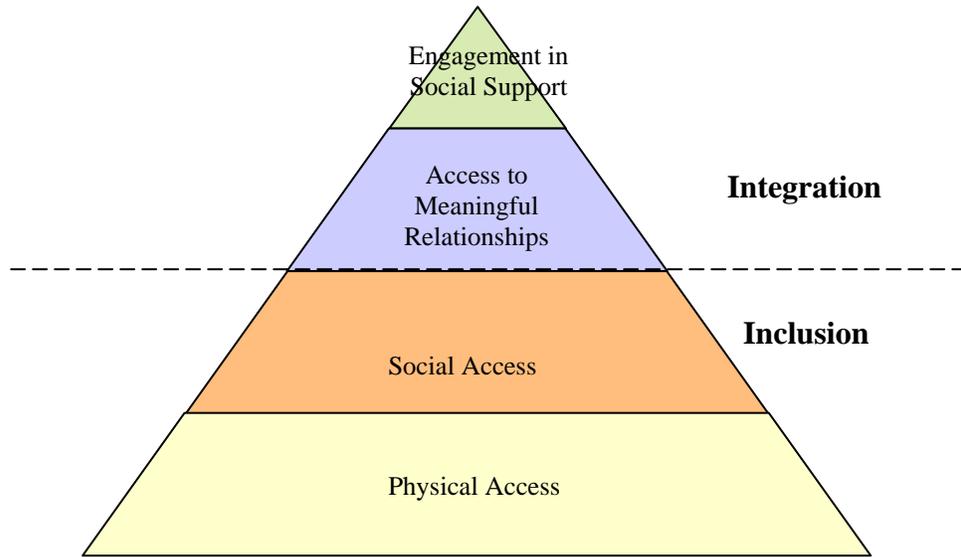
Social role valorization is a systematic schema, based on social role theory, which has attempted to address the issue of individuals who are devalued by others (Wolfensberger, 2000). This concept is based on the idea that the welfare of individuals with disabilities, including mental health issues, depends extensively on the social roles that they occupy. The basic premise involves ensuring that people with disabilities have access to valued social roles in their communities (Wolfensberger, 2000).

It is important to highlight that community integration involves the integration of individuals in the community, both physically and socially. Although for many individuals with mental health issues, physical integration may exist, social integration and inclusion are often lacking (Pedlar, 1990). These individuals may have physical access to the community and experience some degree of social contact. The opportunity to engage in meaningful relationships is often missing, as they find that the majority of their relationships are with professionals within the mental health system (Carling, 1995). There is also limited opportunity for reciprocity in these relationships, whereby individuals with mental health issues are rarely given the opportunity to demonstrate and utilize their strengths to provide and receive social and

emotional support with others. In order to fully achieve inclusion in their communities, older adults with mental health issues must have control over their decisions related to community involvement as well as the care and support that they receive in the community (Basnett, 2001). They must be given the opportunity to fully participate in families, communities, and society (Labonte, 2004). Inclusion relies strongly on the principle of empowerment-in-community (Pedlar et al., 1999), whereby individuals gain control and become empowered to participate fully in their communities.

Lee et al. (2001) have developed a pyramid model of community support which highlights the important distinction between inclusion in community and integration in community (see Figure 1). They suggest that the meaningful relationships necessary for integration can be facilitated through leisure. Social relationships form the basis for many leisure activities since leisure activities often involve dyads or groups of individuals. The leisure pursuit creates a commonality of experience among participants, creating an informal social network of individuals with mutual interests. This social network development, as previously noted, is an important step in the process of community integration.

Figure 1: Pyramid Model of Community Support (Lee et al., 2001)



Fundamental to community integration and inclusion is the removal of the reliance on the professional and the transfer of power to the community members themselves. Advocates of community integration articulate the need to move away from providing service by involving individuals with mental health issues as partners in the process (Carling, 1995; Lutfiyya, 1988). Support services such as peer support and self-help groups can increase feelings of control experienced by the community members and can begin the process of reducing the reliance on the professional and achieving inclusion in the community. Research has demonstrated an enhanced sense of control and self-determination among adults with mental health issues when they were given ownership of their community programs (Hastie & Pedlar, 1993). Feelings of mastery and control have then been found to act as valuable resources in the coping process for individuals with mental health issues and their caregivers (Doornbos, 2002; Pearlin & Skaff, 1995).

The concept of empowerment is central to the process of community integration and inclusion. Empowerment has been defined as “opportunities for, and conditions that, promote choice and control, community integration, as well as valued resources” (Nelson et al., 2001, p. 127). Hastie and Pedlar (1993) describe empowerment as a process in which individuals move from being dependent and powerless to having control over their own affairs. Key elements in the empowerment process are the notions of choice and control, as well as the importance of individuals’ perceptions of the distribution of power in their communities.

Empowerment is a process which can have a powerful impact on individuals with mental health issues and the challenge of community integration. Empowerment has been associated with increased self-confidence and self-esteem, enhanced formal and informal supports, as well as stronger feelings of control and independence (Nelson et al., 2001). Self-determination and decreased feelings of isolation have also been reported as important outcomes of the empowerment process (Carling, 1995; Hastie & Pedlar, 1993).

The principles of empowerment, inclusion, normalization, social integration, and social role valorization are vital to the success of community integration for older adults with mental health issues. Older adults frequently experience role strain, a sense of hopelessness and powerlessness, and social isolation (Gatz, 1995; Lawton, 1994). By adhering to the principle of normalization and ensuring opportunities for participation in valued social roles, empowerment is facilitated. When all of these processes are in place,

community integration becomes a much stronger reality for older adults with mental health issues and their caregivers.

2.5 Constraints and Facilitators

Constraints to community participation (Pearlin & Skaff, 1995) as well as leisure participation (Mannell, 1994) have been examined within the context of older adults with mental health issues. Barriers can be viewed as obstacles that individuals experience in their pursuit of a goal. A constraint may result from the barrier and may intervene in the process and affect the individual's ability to achieve a particular goal (Crawford & Godbey, 1987).

Constraints have been conceptualized as intrapersonal, interpersonal, and structural (Crawford & Godbey, 1987). Intrapersonal constraints come from within the individual and involve psychological states and attributes (e.g., stress, depression, anxiety, and perceived skill). These constraints may affect an individual's preferences and consequently his/her behaviour in relation to such preferences. Interpersonal constraints occur in relation to the interaction between two or more individuals and may affect an individual's preferences and their subsequent behaviours. For example, if an individual is unable to find other participants to join in a team sport, he/she will be constrained in his/her participation in the sport. Finally, structural constraints represent more concrete factors that may intervene in one's pursuit of a goal or activity. These may include a lack of money or work schedules that do not allow time for participation in the activity. These three categories of constraints have also been conceptualized hierarchically by Crawford et al. (1991). They propose that

constraints are first encountered at the intrapersonal level, then the interpersonal level, and lastly at the structural level.

Research related to older adults with mental health issues has described a number of constraints to community participation, inclusion, integration, and leisure participation.

McGuire (1984) proposed five main constraint categories for older adults with mental health issues. These are as follows:

- external resources (e.g., money, information, community resources);
- time;
- approval (e.g., from friends and family, fear of making a mistake);
- social/ability (e.g., skill level, not having someone to participate with); and
- physical well-being.

More recently, attitudinal barriers have appeared particularly prevalent, including stigma and negative social roles (Bedini, 2000; Pearlin & Skaff, 1995). These can lead to a wide variety of constraints, including feelings of loneliness, boredom, and social isolation (Carling, 1995), financial and employment barriers (Mallik, Reeves, & Dellario, 1998), lack of self-confidence, and decreased motivation (Hastie & Pedlar, 1993).

One major constraint experienced by older adults with mental health issues is stigma. Stigma has been defined by Goffman (1963) as a characteristic of an individual, or group of individuals, whose discrediting effect is extremely extensive. This characteristic is often viewed as a failing, shortcoming, or handicap. It reflects a core set of negative attitudes and beliefs that have been internalized by the general public (Carling, 1995). This stigma often leads society to discriminate against individuals who possess this characteristic.

Individuals with mental health issues have been stigmatized for hundreds of years. They have been labeled and devalued in society, feared by the general public, and portrayed as violent, unproductive, and dysfunctional in the media (Carling, 1995; Page & Day, 1990). Stigma has been perpetuated by our legal structures, service models, and the organizations and institutions put into place to “deal” with mental illness.

Stigma has had far-reaching consequences for older adults with mental health issues. This population has been doubly disadvantaged. On the one hand, they have been labeled as mentally ill and excluded because of society’s fear and ignorance about mental health issues. Secondly, they have experienced ageism as society has devalued individuals as they grow older. This continual stigmatization has led to feelings of rejection, social isolation, and exclusion, and has had adverse effects on their self-esteem (Pilisuk, 2001). Prince and Prince (2002) found that individuals’ perceptions of rejection interfered with their sense of belonging in the community. This was especially salient for individuals who perceived lower levels of social support in the community and those who had greater psychosocial skill deficits.

Bedini (2000), in a qualitative study of individuals with physical and/or psychological disabilities, outlined three basic responses to stigma demonstrated by this group. In the worst case, these individuals became helpless in the face of the stigma and became increasingly withdrawn from their community. Others strongly resisted the stigma. They challenged society’s beliefs and attempted to ignore people’s ignorance. They continued to be involved in their community

despite the negative attitudes that they encountered. The third group fell somewhere in the middle where they yielded to, and embraced, their situation. These individuals acknowledged their weaknesses and differences, but also focused on their strengths and abilities. They made efforts to relearn ways to participate in the community in order to accommodate the stigma that they experienced.

Stigma is a pervasive issue in society today. It affects many individuals with disabilities, including older adults with mental health issues and their caregivers (Greene, 1995; Rosen et al, 1995). It acts as a major barrier to community integration and it often results in increased social isolation. Although some success has been achieved in modifying people's attitudes and beliefs, more effort needs to be taken to reduce the stigma and rejection experienced by older adults with mental health issues.

Loneliness, boredom, and social isolation are constraints that are frequently reported by older adults with mental health issues. Unfortunately, these individuals often have extremely small social networks and spend the majority of their time alone (Carling, 1995). As previously mentioned, relationships with professionals in the mental health system often constitute a sizable portion of their social networks. These individuals, consequently, lack the supportive, reciprocal relationships that have been found to positively support individuals in the community integration process.

Some researchers argue that these factors are some of the greatest barriers to community integration (Bridge & Hutchison, 1988; Dugan & Kivett,

1994; Patrick, 1994). Loneliness has been associated with depression, grief, and anxiety and has often been related to transitional life events such as the death of a loved one, retirement, or illness (Dugan & Kivett, 1994). Boredom is commonly reported by individuals with mental health issues (Patrick, 1994). They frequently attribute their feelings of loneliness and boredom to the stigma they experience and the subsequent lack of meaningful opportunities in the community (Davidson et al., 1996). Both loneliness and boredom can become insurmountable obstacles to individuals who have been discharged from the hospital back into the community.

Despite efforts to improve community resources, loneliness, boredom, and social isolation continue to be problematic for individuals with mental health issues. LaVeist, Sellers, Elliot-Brown, and Nickerson (1997) reported that social isolation has shown a strong link with increased mortality among older women with mental health issues. As well, feelings of loss, isolation, and depression have all been implicated as significant risk factors for suicide in older adults (Lapierre, Pronovost, Dube, & Delisle, 1992). The grave nature of these findings speaks to the seriousness of the problem and stresses that these issues can not be ignored among older adults with mental health issues.

It is important to note, however, that in spite of the experience of constraints, many individuals with mental health issues continue to be involved in their community. This may reflect a number of concepts outlined in the leisure literature, including constraints negotiation and facilitators to leisure. Individuals have been shown to continue participation in an activity despite the

experience of constraints related to that particular activity (Kay & Jackson, 1991). Shaw, Bonen, and McCabe (1991) demonstrated that most constraints, other than age, gender, lifestyle, occupational status, and income, did not decrease the levels of participation in leisure activities. Negotiation of constraints has been reported as a strategy for coping with constraints and maintaining leisure participation (Hubbard & Mannell, 2001; Jackson, Crawford, & Godbey, 1993).

Raymore (2002) developed an alternative theory of leisure participation and proposed that individuals may be influenced by facilitators to leisure that encourage or enhance leisure participation. She states that, “the absence of constraints does not necessarily lead to participation” (Raymore, 2002, p. 37). Facilitators are viewed as factors that promote the formation of leisure preferences and encourage participation in leisure activities. Although these facilitators may interact with constraints, they should not be viewed simply as the opposite of constraints, but as a separate and distinct concept. While no specific research has been conducted examining facilitators for individuals with mental health issues, this idea is conceptually relevant to this population and warrants future study. This theory may be useful in understanding factors that positively contribute to community integration for older adults with mental health issues.

Community integration and leisure participation for older adults with mental health issues are processes that are often filled with challenges and constraints. Some individuals may use negotiation strategies to cope with these

constraints and assist in these processes. Others may find themselves employing facilitators in an effort to initiate or maintain involvement in their communities. In either case, little research has applied these principles directly to older adults with mental health issues. The findings from this study will attempt to shed some light on factors that influence community integration for these individuals.

The constraints related to community integration that are experienced by these individuals are further intensified with recidivism. Recidivism has been defined as “the relapse of a disease, symptom, or behavioural pattern that results in the readmission of a patient to a treatment program” (Polk-Walker, Chan, Meltzer, Goldapp, & Williams, 1993, p.164). Although often associated with criminal behaviour and readmission to correctional facilities, this term has also been used in reference to individuals with mental health issues. Relapse and consequent hospital readmission are a reality for many. A variety of factors contribute to recidivism in mental health, including:

- chronicity of the mental health issue;
- lack family support;
- lack of participation in aftercare;
- lack of compliance with medication;
- leisure and community participation;
- length and number of previous hospital admissions; and
- deinstitutionalization with inadequate supports (Gibson, 1999).

The number of previous hospital admissions has been found to be the strongest predictor of recidivism (Polk-Walker et al., 1993). This may reflect the chronic nature of many mental health issues as well as the lack of success that many individuals have in the process of community integration.

Deinstitutionalization has played a significant role in the recent increase in

recidivism among individuals with mental health issues (Segal et al., 2002). Recidivism rates have climbed from 25% to 75% (Bachrach et al., 1994) and hospital stays have decreased in length dramatically since deinstitutionalization began (Veltman et al., 2002). Despite efforts to improve the supports within the community, recidivism rates remain high.

Compliance with medication has shown mixed effects as reported in the recidivism literature. In the past, medication compliance was found to be related to increased community tenure (Carling, 1995), especially among individuals with schizophrenia. In a study of 121 individuals with mental health issues readmitted to California hospitals, however, Segal et al. (2002) found compliance with medication and/or treatment regimen to be unrelated to hospital readmission. A supportive family environment, social support, and participation in aftercare programs have been shown to be stronger predictors of reduced recidivism (Appleby et al., 1993; Gibson, 1999; Segal et al., 2002). Other community resources such as leisure activities, community support programs, and case management have also been shown to decrease the rate of relapse among individuals with mental health issues (Fisher et al., 1992; Franklin et al., 1975; Gibson, 1999).

Recidivism remains a considerable obstacle to community integration. Frequent readmissions to hospital repeatedly remove individuals from their community and often from their support networks. Deinstitutionalization, along with a variety of other factors, have played a substantial role in the high rates of recidivism experienced by individuals with mental health issues. Although none

of the studies identified here specifically examined older adults with mental health issues, my clinical experience has lead me to understand that recidivism also affects this population.

2.6 Social Support

Older adults with mental health issues often have small social networks and, as suggested above, frequently report feelings of isolation and loneliness. Relationship difficulties are also common (Pilisuk, 2001), causing significant distress among both individuals with mental health issues and their caregivers. Green, Vuckovic, and Firemark (2002) indicated that having a limited number of caregivers and feeling socially isolated placed individuals at increased risk for negative mental health outcomes.

The perception of social support has significant implications for individuals with mental health issues. Social support can be of a formal or informal nature. Formal social support systems consist of professionals and volunteers within the community mental health system. Informal social support is equally valuable (Carling, 1995) and comes from friends, family, and other community members. Individuals with disabilities have indicated that they benefit from caring and compassionate relationships with professionals in the community (Pedlar et al., 1999). Although these relationships can be supportive and rewarding for both the individuals and the professionals, a strong desire remains for reciprocal relationships in the community-at-large. Specifically, individuals with disabilities voiced a need for intimate, adult relationships that can satisfy their needs for love and companionship (Pedlar et al., 1999).

Social support has been positively related to quality of life and enhanced mental health of both individuals with mental health issues (Oliver et al., 1996) and their caregivers (Doornbos, 2002; Pearlin & Skaff, 1995). Individuals who feel supported within the community tend to have more satisfying experiences with community integration. For example, Iso-Ahola (1994) states that individuals who experience high degrees of social support have fewer psychological and somatic difficulties following a stressful event. As well, individuals who receive formal support within the community have been found to have fewer hospitalizations than those who do not receive this type of support (Oliver et al., 1996). Fewer hospital readmissions positively impact the success of community integration.

It is important to note that, despite the fact that older adults with mental health issues benefit from receiving support in their communities, it is equally important that these individuals engage in meaningful relationships so that they also have the opportunity to provide support to others. Support networks and clusters not only have a positive effect on the individuals who receive support but also create feelings of self-esteem and self-worth among individuals who are able to give the support (Ochocka & Lord, 1998). It contributes to their sense of well-being and facilitates the development and maintenance of friendships (Pedlar, et al., 1999). Social support, combined with the myriad of feelings that it promotes, plays a valuable role for older adults with mental health issues as well as their caregivers in the community integration process.

2.7 Leisure

As noted earlier, the benefits of leisure satisfaction on individuals' mental health have been well established (Caldwell & Gilbert, 1990; Hull, 1990; Iso-Ahola, 1994). Given the frequent association between leisure and feelings of independence, control, and a sense of belonging, leisure can play a unique role in the lives of individuals with mental health issues (Kelly & Godbey, 1992). Hastie and Pedlar (1993) found that leisure involvement facilitated socialization and companionship among individuals with mental health issues and was associated with enjoyment, contentment, and relaxation. As well, participation in leisure activities has been shown to be negatively correlated with severe anxiety and depression symptoms (Ponde & Santana, 2000).

Leisure participation has been theorized as a buffer against stress (Wheeler & Frank, 1988). Specifically, participation in cultural and social activities was found to buffer life distress (Caltabiano, 1995) and contribute positively to psychological well-being. Leisure has also been found to be associated with positive and desirable moods (Mannell, Zuzanek, & Larson, 1988). Mood, in turn, has been found to influence attention, cognition, and behaviour (Hull, 1990).

Leisure can also be extremely useful to older adults in relieving boredom and loneliness. Leisure can provide structure to the individuals' lives and facilitate social interaction with others who share common interests (Datlow-Smith & Belcher, 1992). The effects on community integration have been shown to be both direct and indirect. Leisure has been shown to increase

feelings of control and self-esteem and improve mood (Compton & Iso-Ahola, 1994; Schleien & Tipton Ray, 1988), indirectly enhancing social integration. As well, it has directly decreased feelings of boredom and loneliness (Searle, Mahon, Iso-Ahola, Sdrolas, & VanDyck, 1998) in adults with mental health issues.

Leisure involvement has the potential to contribute positively to the experience of community reintegration. Lee et al. (2001) suggest that the meaningful relationships necessary for integration can be facilitated through leisure. Social relationships form the basis for many leisure activities. The leisure pursuit can create a commonality of experience among participants, creating an informal social network of individuals with mutual interests. This social network development, as previously noted, is an important step in the process of community integration and inclusion.

Evidently, the majority of research examining the effects of leisure has focused on leisure's positive contributions to mental health and psychological well-being. Recent research, however, has critically examined these theories and assumptions. Leisure has been found to have negative impacts on individuals in certain situations. For example, leisure has been shown to perpetuate negative social roles and stereotypes of marginalized individuals, including women and older adults (Jacobson & Samdahl, 1998). As well, some forms of leisure such as gambling and consuming alcohol can have detrimental effects on individuals if addictive behaviours develop (McNeilly & Burke, 2001). Social interaction and social support can also be negatively affected by

some forms of leisure. Although the findings from some studies examining internet use indicate enhanced feelings of social support (Silverman, 1999), research has also shown decreased interaction and support among internet users (Swickert, Hittner, Harris, & Herring, 2002). Despite the fact that most research expounds the positive effects of leisure, it is important to be sensitive to potential negative implications of leisure for individuals with mental health issues.

In summary, community integration is an important aspect of the transition from inpatient psychiatric units back to the community. The concept of community integration is central to this research study. As well, a variety of factors have been shown in the literature to contribute to community integration, both positively and negatively. As I embarked on this research, I was sensitive to the theories and ideas underlying the concepts of community; community integration; deinstitutionalization; constraints and facilitators; recidivism; social support; and leisure. In addition to this theoretical sensitivity, I entered this study with experiential knowledge which had sensitized me to the challenges faced by older adults with mental health issues. Having worked as a Therapeutic Recreationist on an inpatient psychiatry unit, I was heavily involved in the discharge process and attempted to facilitate the connection of these individuals to community leisure resources. I was also aware of the difficulties experienced by these individuals when they were unable to sustain their involvement in the community and required readmission to the hospital. It was this experience that prompted me to embark on this journey in order to gain a

better understanding of the community integration process for these older adults.

Qualitative research methods were used to explore the experience of community integration for older adults with mental health issues. I was privileged to have been able to share in the stories of five older adults and their experiences of returning to the community after an inpatient hospital stay. These older adults provided me with valuable insight into the process of community integration. These findings are grounded in the stories of the participants. The qualitative methods employed in this study, including the research questions, recruitment, data collection and analysis will be explored in detail in the following chapter.

CHAPTER 3: METHODS

3.1 Purpose

As previously outlined, the purpose of this study was to develop an understanding of the experience of community integration for older adults with mental health issues. Older adults in this study included adults aged 55 years and over. Community integration was examined as the participants made the transition from an inpatient psychiatric unit back into the community. “Successful” community integration was not defined by the researcher and was not a prerequisite for participation in the study. In accordance with the tenets of interpretive research, the participants’ meanings and perceptions of moving back into the community were used as the basis for understanding the process.

3.2 Research Questions

Questions focused on the lived experience of the participants, so that they could identify factors that they believed to have facilitated or hindered their integration into the community after a brief stay in a hospital setting. The inpatient psychiatry unit from which participants were recruited was a short-stay unit described in detail in Chapter 1.

The study also intended to explore the experiences of the caregivers of these individuals in order to understand their perceptions of the process of community integration for the individuals with mental health issues. The purpose of these interviews was not to fully examine the community integration experience of these caregivers. Rather, these interviews were to be used to gather information from the caregivers about their perception of the process for

the individuals with mental health issues. Unfortunately, I was unable to recruit and interview any caregivers for this study. This issue will be discussed in detail in Section 3.5.

The research questions guiding this study were:

1. What was the experience of moving back into the community for these older adults, following discharge from an inpatient psychiatric hospital setting?
2. What were the perceptions of the caregivers related to the experience of moving back into the community for these older adults?

In order to answer these two main research questions, the five questions that follow were used to guide the research process. These were as follows:

- i. What was the discharge process like?
- ii. What has the process of moving back into the community been like?
- iii. What has helped in the process of community integration?
- iv. What has hindered the process of community integration?
- v. Are there any suggestions for change to the process?

Research Question #1: What was the discharge process like?

This question helped the researcher to better understand the immediate experience of leaving the hospital and moving back home into the community. Probes focused on how ready the individual felt to be discharged, any services that were in place to support the individual in their transition, as well as any

services that could have made the transition easier (refer to Appendices A & B for Interview Guides).

Research Question #2: What has the process of moving back into the community been like?

This question addressed the broader experience of community integration that has occurred since the time of discharge. Questions focused not on the actual discharge from the hospital but rather on the longer period (approximately 3 months) of being back home in the community. I hoped to gain an understanding of various issues that these individuals had faced since leaving the hospital, including physical and psychosocial issues (e.g., physical health, family support, financial issues). Probes here addressed issues related to what a typical day included for these individuals, with the hope of exploring what types of activities these individuals were involved in. I also hoped to understand the aspects of these activities or services that had been helpful (e.g. social support, social contact through leisure, connection to health care services for follow-up).

Research Question #3: What has helped in the process of community integration?

With this question, I hoped to discover any factors that had been helpful in the process. Questions focused on social support, leisure activities, continued contact with health care providers, and adherence to medication routines. As well, probes were used to examine whether the individuals felt that they had been successful in the process of community integration to date.

Research Question #4: What has hindered the process of community integration?

This question addressed the issue of constraints and barriers to community integration. Probes were related to feelings of loneliness, isolation, and boredom; stigma; and social support. As well, issues related to physical well-being, finances, and access to community services were examined.

Research Question #5: Are there any suggestions for change to the process?

The participants were asked to provide suggestions relative to those factors or services that they felt could have assisted them in the community integration process. Questions related back to those constraints and facilitators that questions 3 and 4 had explored and provided the individuals with an opportunity to suggest any other approaches or services that would have been helpful in the process of community integration.

3.3 Guiding Conceptual Framework

This inductive research employed qualitative methods to explore the experiences of community integration for older adults with mental health issues. The study was guided by the conceptual framework of phenomenology, focusing on the lived experiences of these individuals (Patton, 2002). A small number of individuals provided a rich and detailed account of their experiences with community integration through individual interviews. This is a key principle within the phenomenological approach as outlined by Moustakas (1994).

Phenomenology originated mainly in the fields of philosophy and sociology but has begun to be used more frequently within other disciplines such as leisure studies. This framework attempts to understand social phenomena from the actor's own perspective (Patton, 2002). This study attempted to understand the process of community integration from the perspective of older adults with mental health issues, as well as to gain an understanding of the perspective of the caregivers of these individuals since research has shown that caregivers often play a significant role in the community integration process.

Consistent with the phenomenological approach (Creswell, 2003), the study sought to discover the meaning, structure, and essence of the lived experience of community integration for older adults with mental health issues. The study was retrospective in that the experience was interpreted at the time of the description. Phenomenology relies on this approach to data collection since individuals are unable to engage in deep reflection about the overall impact of the experience while they are living the phenomenon (Patton, 2002).

In phenomenological research, the researcher does not impose his/her values, attitudes, or beliefs on the study participants. The participants construct their own meanings and descriptions of the experience. Reality is neither what the literature has demonstrated nor what the researcher believes. Reality is what the participants believe it to be (Patton, 2002). The researcher must refrain from judgment and stay away from the ordinary way of perceiving things. This is an important step in phenomenological research and is referred to as epoche (Patton, 2002).

The key concepts that were investigated included the process of moving from the hospital back into the community, as well as the feelings and emotions that were experienced throughout the transition. As noted earlier, the study will attempt to discover factors that were helpful in the process of community integration as well as those that hindered the process.

An interview guide outlining these key areas of investigation was developed (see Appendices A & B). Within the framework of phenomenology, however, the researcher must be careful not to impose preconceived ideas or beliefs on the study participants. The interview questions acted only as a guide to me as I interviewed each participant. Through the process of interviewing, the interview questions developed according to the issues that the participant indicated as most salient to them.

3.4 Data Collection

Information Letters outlined the purpose and requirements of the study (see Appendix C). These letters were given to each individual who was discharged from the unit and returned to his/her home in the community. To preserve participant anonymity, the Therapeutic Recreationist on the unit distributed the letters and explained the study to the clients (see Appendix D for Client Recruitment Script). If the client was interested in participating, he/she signed a statement of interest attached to the Information Letter and provided his/her name and telephone number which was forwarded to me in a pre-stamped envelope. This form gave me permission to contact the individual approximately three months after discharge to arrange a time for an individual

interview. This form, however, in no way obligated the individual to take part in the interview at that time.

If the individual agreed to participate when contacted by me three months after discharge, we arranged a time for an individual interview. At that interview, the individual was reminded of the purpose and requirements of the study and signed a consent form for participation in the interview (see Appendix E). These interviews were all tape-recorded, with participant consent, and then transcribed verbatim. The participants chose the location for their interviews. Three of these interviews occurred in the participants' homes and two interviews took place at the hospital.

At the conclusion of the interview, the individual was asked to sign a consent form giving permission to contact him/her by telephone for follow-up to verify my interpretation of the interview (see Appendix F). As well, as mentioned above, the individual was asked to give the name of a caregiver, who had been involved in his/her community reintegration process and who could be contacted for an interview. This approach to recruitment was taken because, in my experience as a Therapeutic Recreationist on this particular unit, clients often indicated that they did not want staff to contact their caregivers directly. The clients preferred to contact the caregivers themselves and the caregivers would then contact the staff on the unit. Individuals were not excluded from the study if they did not want their caregiver to be contacted or if they did not have a caregiver who was willing to participate in the study. All participants were

given a feedback letter following the completion of their interview (see Appendix G).

Following each interview, as part of the data analysis process, oral member checks were done with each participant. I telephoned each participant and confirmed the content of our initial interview and presented them with preliminary themes and analysis of the data to date. Detailed fieldnotes and a reflective journal were maintained throughout this process, the data from which helped to further inform the emergent understanding of participants' experiences. Upon completion of the study, an executive summary of the findings was mailed to all participants.

3.5 Participants

Participants for this study were individuals with mental health issues who had had a previous admission to a short-stay inpatient psychiatric unit at a geriatric hospital in Toronto, Ontario. For the purpose of this discussion, individuals with mental health issues were referred to as clients. This is the way in which the hospital refers to these individuals. As well, it provides some clarity in the discussion by allowing for the distinction among the participants between clients and caregivers.

Purposeful sampling was undertaken to recruit participants for this study. The participants were selected from all clients who had been discharged back to their home within the community for a period of at least 3 months. I chose a 3 month time period in order to allow the clients a period of time to settle at home and experience life in their communities after discharge. This ensured

that the participants had spent a significant period of time in their community in order to provide adequate detail of their experiences there. Clients who were discharged from the hospital to nursing homes or other long-term care facilities were not included in the study. The concept of community is quite different in these facilities and the types of support available can also differ. For example, communal living arrangements such as common living and dining areas can contribute to a sense of community quite different than that experienced by individuals living in their own homes. For the purpose of this study, I was interested in the integration back into the broader community.

Participants were clients aged 55 years and over who had been diagnosed with a psychiatric disorder and who had received inpatient treatment at the hospital within the last year. This time period was chosen in order to sample individuals with whom I had not been involved with as the Therapeutic Recreationist on the unit. These individuals were discharged back to their homes from the unit at least three months prior to the interviews, as discussed earlier. Only individuals who were deemed competent to give consent by the staff psychiatrist were recruited for this study. Aside from this, there were no cognitive requirements in order to participate. It was understood, therefore, that some of the participants may have been experiencing some memory difficulties at the time of the interview. It was felt that, despite the possibility of a slightly inaccurate recollection of the process of leaving the hospital, the experiences of these individuals were as relevant as those of individuals with no cognitive impairment. The reality was that of the individual. Although insight into the

discharge process was valuable for this study, it was also important to understand the present situations of these individuals and gain insight into their current experiences.

I had hoped to recruit 8-10 clients to participate in the study. We began recruiting (following the process described in Section 3.4) in April, 2003. The Therapeutic Recreationist on the unit distributed information about the study to all clients who met the criteria for inclusion. During the period of April, 2003 through the end of December, 2003, only 11 clients met these criteria. This number was much lower than expected with the majority of clients being discharged during that time to nursing homes, retirement homes, or other supportive living communities, not back to their homes in the community.

Of these 11 clients who were discharged to their homes in the community, 6 initially agreed to participate. One client had agreed initially (upon discharge) but when I contacted her 3 months later to arrange an interview time, she was experiencing a relapse and no longer wanted to participate in the study. This meant that participants for this study included five older adults, four females and one male. These individuals ranged in age from 67-79 years. One individual was married, 1 was divorced, and 3 were widowed. Two of these individuals had had multiple admissions to psychiatric facilities in the past year. Each participant had been living back in the community for a period of three months prior to our interview. All of the participants had children with whom they described having close relationships.

All of the participants had been diagnosed with depression or bipolar mood disorder. Although each participant was unique, all five participants had experienced similar issues related to their mental health. These issues and experiences would likely have been quite different with a more heterogeneous sample that included individuals with other psychiatric diagnoses such as schizophrenia or personality disorders.

Each of the five participants lived at home in the community at the time of their interview. Despite various issues that they were experiencing (which will be described in detail in Chapter 4), they were coping well with their mental health issues and indicated that they were functioning well at home.

Consequently, it is important to note that all of the participants in this study generally described very positive experiences of being back home in their community. The results would likely have differed greatly if the study had been able to include individuals who had not had such positive experiences or who had relapsed and returned to hospital. This issue will be discussed in detail in Chapter 6.

As indicated above, I also intended to conduct interviews with one caregiver of each participant. For the purpose of this study, a caregiver could have been anyone, paid or unpaid, who acted as a main support person for the client. This could have included spouses, children, siblings, paid companions, or other community members such as friends, clergy, or volunteers. Following the process outlined in the Data Collection section, at the conclusion of the client interview, I asked each client if he/she would agree to have me contact

their caregiver to discuss possible participation in an interview. The purpose of these interviews was to provide a broad view of the transition from hospital to community through the eyes of the caregivers.

In four cases, the caregiver most involved in the community integration process was a daughter or daughter-in-law. In the fifth case, this person was the client's wife. Four of the five clients refused to allow me to contact their caregiver. All of the clients who refused stated that their caregiver was already too busy and that they did not want to burden them by asking them to participate in the study. In the case of the one client who allowed me to contact her caregiver, numerous telephone calls and messages that I left were unreturned. Consequently, no interviews were conducted with the caregivers of these individuals.

3.6 Data Analysis

A grounded theory approach (Strauss & Corbin, 1990) was utilized to analyze the data from this study. Insights arising from the analysis were grounded in the data, provided by the participants in the study, that had been systematically gathered and analyzed. This was accomplished using the constant comparative method as outlined by Glaser and Strauss (1967). The constant comparative method guided me to a set of coding procedures that assisted in providing some standardization and rigor to the analytical process (Strauss & Corbin, 1998). This method consisted of four main stages: comparing incidents applicable to each category, integrating categories and their properties, delimiting the theory, and writing the theory. As well, the data were

systematically compared to the current literature on community integration. This comparison assisted in theory development and helped me to make recommendations for future research and practice.

In order to facilitate the development of categories and comparison of incidents applicable to each category, data were stored and organized as outlined by Kirby and McKenna (1989) using Microsoft Word word processing software to store all files. Passages or quotes from the interview transcripts, fieldnotes, or reflexive journal were treated as bibbits. Bibbits are pieces of data that can stand on their own and convey a message from within the data (Kirby & McKenna, 1985). These bibbits were loose bits of data that were grouped together into categories with other bibbits that conveyed similar information or ideas. A single bibbit, or piece of data, may have contained several properties. For example, one quote from an interview may have contained a number of different ideas, or properties (Kirby & McKenna, 1985). Groups of bibbits that had common properties or meanings were then grouped into a category that represented the shared meaning among the bibbits.

All data or bibbits, including those from interview transcripts and fieldnotes, were analyzed and participants' responses were coded using an open, axial, and selective coding method (Strauss, 1987). The initial type of coding conducted in the process of data analysis was open coding. This was unrestricted coding whereby I developed broad themes or concepts that described the data. These codes were extremely tentative and were refined in the process of axial and selective coding. Axial coding consisted of the intense

analysis of each category generated in the open coding process. This resulted in subcategories or the creation of new categories. Selective coding followed and related to the systematic and concerted coding process wherein the core category or main theme emerged from the data. This resulted in delimiting the data to include only codes that related specifically to the core category.

The coding process included analyst derived codes as well as codes taken directly from the words of the participants, namely “in vivo” codes. Broad themes were identified, categorized and analyzed. Throughout the process of data analysis, I was sensitive to negative cases within the data. A negative case can be any element within the data that disconfirms the hypotheses or conclusions that have been developed. Negative case analysis is an important technique for ensuring trustworthiness in qualitative analysis. It can be viewed as a “process of revising hypotheses with hindsight” (Lincoln & Guba, 1985, p. 309). I continuously reviewed and revisited the emerging themes and hypotheses that developed throughout the process of data analysis. This process continued until the themes were consistent across all of the participants. This process helped to refine the themes and hypotheses in the study until I was confident that all known cases without exception had been addressed.

Analytical memos were kept throughout the process of data analysis to assist in the delineation of emerging patterns and themes. Hurricane thinking, as outlined by Kirby and McKenna (1989) was a useful tool in organizing the themes from the interviews. Salient responses and themes were identified, followed by the delimitation of irrelevant or overlapping data. The data

continued to be coded and the categories were compared until theoretical saturation was reached. Theoretical saturation occurred when additional analysis failed to discover anything new about the categories (Strauss, 1987).

Theory development was the final stage of the data analysis. This study has generated emergent theory from the data gathered from the participants. Analysis of the participant interviews has provided insight into the factors that both limit and facilitate community integration for individuals with psychiatric disorders.

3.7 Trustworthiness

This study, like many qualitative research studies, utilized a natural setting for data collection whereby the researcher was an instrument of the study. It was vital, therefore, that trustworthiness and authenticity were emphasized (Patton, 2002). This involved being balanced, fair, and conscientious in taking account of multiple perspectives, interests, and realities (Lincoln & Guba, 1986, as cited in Patton, 2002).

Trustworthiness in qualitative studies can be enhanced by ensuring transferability, rigor, dependability, confirmability, and credibility (Lincoln & Guba, 1985). Although the findings from this study are not meant to be generalized to the general population, they may be transferable and used in the future to compare experiences of similar individuals who are involved in other programs or other communities. I have tried to ensure potential transferability of the findings by providing a thick description of the processes and findings of the study.

Rigor involved identifying personal biases and maintaining an awareness of these biases throughout the research process. As previously mentioned, my experience as a Therapeutic Recreationist had sensitized me to the challenges confronting individuals with mental health issues. I was aware of the therapeutic role and was able to remain open to the experiences of the participants. Keeping a reflective journal throughout the process also helped in identifying any personal feelings or emotions that may arise throughout the course of the study. For example, I needed to repeatedly remind myself that I was the researcher, not the therapist. I had to remember to focus on asking the questions, rather than providing suggestions or advice to the participants (reflexive journal, December 3, 2003).

Dependability and confirmability were enhanced through the maintenance of a thorough audit trail (Lincoln & Guba, 1985). This audit trail was comprised of raw data, including fieldnotes, audiotapes, and transcriptions from the interviews. Process notes describing the methodology and process of the data analysis were also maintained throughout the study. Data synthesis and analysis products, such as draft write-ups, memos, notes, and summaries of the data analysis process, were included in the audit trail. Data reconstruction and synthesis products that were also key components in the audit trail. These notes kept a record of the structure of the categories and the themes and conclusions that emerged from the data. The reflective journal and analytical memos contributed to confirmability by providing a record of activities and feelings throughout the analysis process.

Credibility in the study was vital and was supported through the persistent analysis and review of the interpretation of the research participants' contributions to my understanding. Interviews were conducted with the participants until theoretical saturation was reached, whereby the interviews were generating no new information. Finally, oral member checks were conducted by telephone with all participants in order to verify the interpretation of the findings.

Qualitative research is often subjective and inductive in nature. Conscious attention, therefore, is required to ensure that the study design and data analysis occur in a fair and thorough manner. By addressing the issues of transferability, rigor, dependability, confirmability, and credibility, authenticity and trustworthiness are more evident. A thick description of the findings is provided in Chapter 4. Detailed discussion and synthesis of the findings are presented in Chapter 5.

CHAPTER 4: FINDINGS

4.1 Introduction

Data were collected over a five month period, from November 2003 to March 2004. Data consisted of in-depth, semi-structured interviews and oral member checks with each of the five participants. In addition, detailed fieldnotes were maintained throughout the process, as well as a reflective journal, which addressed methodological issues and personal reflections of the process.

Findings from these interviews are presented in this chapter. As previously noted, no caregivers participated in the study. Consequently, all data were obtained from the older adults with mental health issues. This chapter will describe each participant and present the findings from the interviews with these individuals. The findings are thus grounded in the stories of the participants. Direct quotations are included to illustrate trends and themes contained in the data. Further discussion of these themes along with the emerging theory will be examined in detail in Chapter 5.

4.2 Participants

The following five participants were former clients of the inpatient psychiatry unit. As previously noted in Chapter 3, all of these individuals had been living in their homes in the community for a period of three months after their discharge from the hospital. Participants are identified by pseudonyms to protect their anonymity.

- Kathy was an 80 year-old woman living in an apartment with the support of a paid, live-in caregiver. She required 24 hour/day care in order to complete her activities of daily living, including bathing, dressing, and cooking. She had been diagnosed with depression that was being treated with medication. Kathy was able to ambulate with a walker in her apartment but had experienced several falls since she had been discharged from the hospital, one such fall requiring further hospitalization. She indicated that she was dealing with a variety of physical health issues, including back pain and sleeplessness. She exhibited some confusion during our interview, such as not being able to accurately remember the dates and sequence of her various hospitalizations. Kathy's husband had passed away approximately 1 ½ years ago but she stated that she was coping well and that, "time heals all wounds" (interview, November 28, 2003). Kathy had one daughter and two granddaughters who lived in the city and visited regularly. She was extremely proud of all of them.
- Winnifred was a 77 year-old woman living alone in her own apartment. She had been a widow for eight years. She had been living in the United States (U.S.) for the past ten years and recently moved back to Canada because health care was more affordable here. She had a very close relationship with her daughter who lived in the U.S. Two of her sons lived in Toronto, however, Winnifred indicated that her relationships with her sons were not as supportive as the one she shared with her

daughter. Winnifred indicated that she had a few friends in Toronto but that most of her friends still lived in the U.S. She had been diagnosed with bipolar mood disorder which was managed well with medication. She had had multiple hospital admissions (at least 2 in the past year) and she was followed closely by one of the psychiatrists from the inpatient psychiatry unit at the hospital. She led a fairly active social life but also stated that she liked having time to herself.

- Penny was a 78 year-old woman living alone in her own apartment. She was also a widow. She had spent most of her life in Canada but she had lived in Israel recently. She had one daughter who lived in Israel and a son and daughter-in-law who lived in Toronto and were very supportive. Penny had a small social network of friends in the city and she was currently participating in a course at a community centre in the city. She had been recently diagnosed with depression and anxiety. She had been unable to find adequate psychiatric care in the community and was consequently admitted to the inpatient psychiatry unit at the hospital. After discharge from the inpatient unit, Penny attended the Psychiatry Day Hospital program as an outpatient for 3 ½ months.
- Henry was a 68 year-old man who was married and lived with his wife in their own home. He had a supportive relationship with his wife and had one grown son who still lived at home. He also had one daughter who was married and lived outside the family home. Henry had recently been diagnosed with depression and was having some challenges managing

the side effects of his medications. Shortly after being discharged from the hospital, Henry had developed Bell's Palsy. This had presented a variety of physical health issues such as partial paralysis of his facial muscles and extreme dryness and sensitivity in his eyes. Henry indicated that he was coping fairly well with both his physical and psychiatric issues but that he was "not quite 100 percent yet" (interview, February 25, 2004). He was followed closely by the community psychiatry team from the hospital after discharge from the inpatient psychiatry unit.

- Ruth was a 72 year-old woman who lived alone in her own apartment. She had been married once but divorced, stating that it had not been a good relationship. She had one daughter who lived in western Canada. She described this relationship as very supportive. Other than the relationship with her daughter, Ruth did not have close relationships with any other family members. Relations with her two sisters had become strained in the past few years. Ruth had been diagnosed three years ago with depression and had experienced multiple hospital admissions for treatment. She had a couple of very close friends who had been very supportive throughout her hospitalizations including following her return home after her most recent hospital stay. She was active in her synagogue prior to her diagnosis and remained involved after her discharge from hospital this winter. Like Henry, Ruth had also been followed by the community psychiatry team from the hospital after discharge from the inpatient psychiatry unit.

All of these participants were pleased to meet with me and share their stories. Many of them were interested in the research process and asked about my experiences with research and what I was trying to understand from my findings. It was the openness of these individuals and their willingness to share their experiences, both positive and negative, which allowed me to gain insight into the process of community integration. Analysis of the data gathered in the interviews, fieldnotes, and reflexive journal led to the emergence of themes and patterns that will be discussed in the following sections.

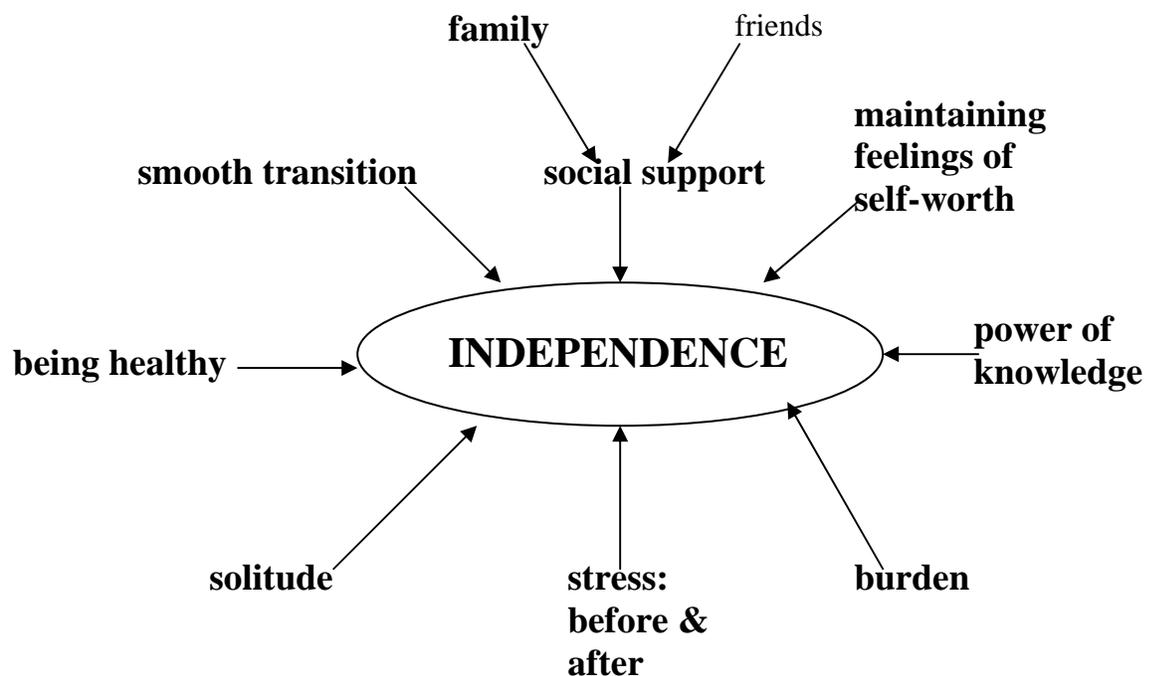
4.3 Overview of the Findings

In utilizing a grounded theory approach (Strauss & Corbin, 1990), the findings from the data gathered from these older adults with mental health issues were analyzed and grouped into nine themes. Hurricane thinking, as outlined by Kirby and McKenna (1989), was useful in helping me to organize these themes around the eye of the hurricane or the core category. At the centre of all of the themes was the concept of independence. This core category emerged strongly in the very first interview and continued to be the most salient, meaningful issue throughout the rest of the interviews. The other eight themes all relate to this concept. These themes are outlined in Figure 2 and are as follows:

- Independence
- Being Healthy
- The Power of Knowledge
- Smooth Transition

- Social Support
- Burden
- Stress: Before and After
- Maintaining Feelings of Self-worth
- Solitude

Figure 2: Hurricane Thinking (Kirby & McKenna, 1989)



4.4 Independence

The core theme that emerged from the data centred on the concept of independence. It is an in vivo code that all of the participants focused on throughout their interviews. They each stated that the reason they had been successful in preventing relapse and achieving community integration was because they were independent and in control of their lives. Their independence

was apparent in a number of different ways, including their strong quest to gain knowledge about mental health and how to prevent relapse as well as in the emphasis that they placed on being healthy and managing stress. The importance of the smooth transition from the hospital back home into the community and their desire to maintain feelings of self-worth also highlighted the value that the participants placed on independence. Finally, their concern about being a burden to their families emphasized the constant pursuit of independence among all of the participants.

The concept of independence that the participants spoke of was very individual and, at times, quite different from mine as a health care professional. For example, Kathy required a live-in caregiver 24 hours/day to assist various activities of daily living. She was unable to prepare her own meals, bathe or dress herself, or even ambulate within her own apartment. She had only left her apartment twice in the three months prior to the interview because of the difficulty she had managing the stairs leading out of her apartment.

As I sat speaking with Kathy, I was surprised at her level of dependence on her live in caregiver. She required assistance with all aspects of her activities of daily living. In my head, I immediately began to think about which health care professionals I should call to get help for this woman. Much to my surprise, she didn't want their help. She was "independent"!! How her idea of independence and mine were so different amazed me. Her criteria for independence were completely different from what I had been used to working within a multidisciplinary team of health care professionals. As I left her apartment and returned to my car, I sat and reflected on her concept of independence and I smiled at the difference between being the therapist and being the researcher. (reflexive journal, November 28, 2003)

Despite the multitude of physical health issues that Kathy was dealing with, she was adamant that she was independent living in her own apartment.

Kathy: And I don't think I would be able to do more. Because my back has terrible damage. I am happy I can stay at home with help. Because I know some other people, they can't afford the help. I don't know how they manage.

Shannon: And you're happy you're here at home? What if you had to be in a nursing home or something?

Kathy: No [adamantly]. I'm happy at home.

Shannon: You would rather be here?

Kathy: Yes.

Shannon: And why is that?

Kathy: Because of my surroundings. I have my own television, I can sleep whenever I want, I can phone whenever I want. I am independent.

Shannon: So you have that freedom and independence?

Kathy: Yes freedom. I am independent. (interview, November 23, 2003)

Independence was associated with being in control and having the freedom and ability to make decisions. It was not simply the words that were used, but the conviction in the voices of the participants that made me realize the significance that this concept held for all of the participants.

Winnifred: I do what I want to do. If I want to stay in bed, I stay in bed. If I want to do something else, I do something else. I'm happy. (interview, December 1, 2003)

Ruth: I think that a lot of people, if they have their own homes to go back to, it's good.

Shannon: What is it about being able to go back to your own home that's good?

Ruth: I don't have to be accountable to anybody. I can do as I please. I don't have to worry about not pleasing somebody or be pushed into doing things that I really don't feel is what I need. I know best what I need for myself. (interview, March 1, 2004)

There were many factors that influenced the participants' independence, both positively and negatively. If an issue arose that challenged their independence, such as stress or a physical health problem, the participants were usually able to mobilize a variety of coping resources in order to deal with these challenges. By successfully employing these strategies and maintaining control over their lives, the feelings of control and independence continued to grow and compound. These experiences are outlined in the following section.

4.5 Stress: Before and After

Not surprisingly, stress was a common theme throughout the interviews. Stress was central in two main aspects of the lives of the participants: as influencing the onset of their mental health issues and as something they worked hard to cope with throughout the recovery process. Stress was viewed as a precipitating factor in the participants' mental illness.

Shannon: Did it [the onset of depression] have anything to do with the restaurant?

Henry: Nothing to do with the restaurant. The restaurant doesn't give you depression. The restaurant gives you stress and the stress gives you sleeplessness and depression. (interview, February 25, 2004)

The participants were very aware of the role that stress played in the onset of their mental health issues. In order to prevent future relapses, they were very focused on managing their stress. This was not an easy task and remained

a challenge for all of the participants. Sources of stress included declining physical health and feelings of being a burden on their families. These participants were cognizant of the negative impact that stress could have on their mental well-being and had mobilized a variety of means of coping with the stress. Ruth employed cognitive coping strategies, stating:

So, thank God, I got better. My worry when I went home was that I just wanted to make sure that I don't cause any more stress for my daughter, because she has gone through a very stressful time. So that's why I'm so watchful of my moods. Maybe I'm a bit overworried about it but... I like my independence. It can get kind of lonely at times but I have a lot to do to keep me busy at home to get my life in order. (interview, March 1, 2004)

Leisure was another tool that the participants found to be helpful in managing stress. They spoke of participating in leisure activities in order to keep their minds occupied and focused on things other than their mental health issues.

Shannon: Can you tell me a little about what it was like when you left the hospital to come back home?

Winnifred: Well, it was sort of like I never went to the hospital. I just picked up where I come from. Like, at first it bothered me that I didn't have furniture and it [the apartment] was empty. But then, it's cozy, it's warm, and I'm going to get a sofa. And I go out, I have a few friends.

Shannon: Where do you go?

Winnifred: Well, yesterday I went to the synagogue. They have like singles (laughs).

Shannon: Oh yeah. Is that like a group?

Winnifred: A group, yeah. It was very nice, an excellent speaker. Excellent. So I'm looking for people who are interested in talking about what's going on in the world like in Africa, how the AIDS just

took over completely. And he talks, it was very good, and then they serve a little lunch. And you pay \$ 10.

Shannon: So, do they have a different speaker every week?

Winnifred: No. This one is once a month. But there are different synagogues. So it distracts me and tires me out. Then I come home and make myself something to eat and I read. I'm going back to sculpting. I'm pretty peaceful with myself now. (interview, December 1, 2003)

Leisure was used as a means to an end in order to keep the participants occupied and involved in their communities. Certain leisure activities, such as adult education courses and volunteering also promoted feelings of self-worth, as illustrated in the following section.

4.6 Maintaining Feelings of Self-Worth

All of the participants in this study had worked outside of the home for significant periods of their lives. They spoke highly of these work experiences and reflected on the void that retirement had left in their lives. It was also interesting to note that the onset of mental illness occurred either after these individuals had retired or when they were getting close to retirement. Although none of the participants stated that retirement had been a contributing factor to the onset of their mental health issues, feelings of productivity and self-worth were viewed as strong facilitators to mental well-being.

Ruth: Yes. 1986 actually. My marriage was not good. It goes way back. It may be part of my problem. One thing about when you're on your own, you tend to be alone with your thoughts and you're not occupied, it can be difficult. I'm one that likes to keep busy. I worked beyond age 65. That's one thing I miss, that work environment.

Shannon: What is it about the work environment that you miss?

- Ruth: Well, there's something you're doing that's productive. Here, unless I'm accomplishing something at home in my own affairs, I don't feel that I'm productive enough. I don't have a sense of achievement or self-worth. I have to get into something.*
- Shannon: What are you thinking of?*
- Ruth: Well, maybe on a volunteer basis or taking a course of some kind. But the other problem is that I have a problem with cataracts. That's a bit of a handicap.*
- Shannon: Yeah, it can be a challenge.*
- Ruth: So, it's going straight from being on the work force to being a senior citizen.*
- Shannon: It was a hard transition for you?*
- Ruth: Yes. A very hard transition.*
- Shannon: Do you feel you weren't very prepared for that?*
- Ruth: No, not at all prepared for it. (interview, March 1, 2004)*

To fill the void that retirement had left in their lives, the participants did not express strong interests in the activity-based leisure opportunities that have traditionally been available to older adults. Instead, they were passionate about opportunities for continued learning and education in the form of writing courses, computer courses, and guest speakers. Volunteering was another activity that evoked feelings of productivity and a sense of achievement. Two of the participants were currently involved in these types of activities, while the other three planned on initiating these types of activities in order to maintain feelings of self-worth and self-esteem.

4.7 Solitude

The participants in this study were able to express the value they placed on the leisure activities mentioned above and their desire to maintain feelings of self-worth and productivity. They recognized the strong positive impact that

social support had had on their transition back into the community. Despite these realizations, these individuals still tended to participate mainly in solitary activities on a day-to-day basis. Although many of these leisure pursuits were of a solitary nature, the participants still made use of the activities to help to prevent future mental health relapse. They enjoyed watching television, reading books and newspapers, going for walks, or running errands. Although they said that they did enjoy visiting with friends, this was only on an occasional basis and often required more energy and motivation than the participants were able to give.

Shannon: Have you had any problems or have you had any things that have been hard for you in coming back home after having been in the hospital?

*Penny: I think you're lonelier when you come back home because there is that community in the hospital. Until you replace it with something to do. Like things are laid on for you, but at home, you have to be the one to make the arrangements. So, I don't make too many arrangements, but I do make some. I might suggest a movie or this weekend we went to the fair. Now I didn't suggest that, a friend of mine did. She called to see if I'd like to go. So, it is harder for me now to make dinner or serve dinner to people.
(interview, December 3, 2003)*

Loneliness was mentioned but was not a major concern for these individuals. They enjoyed the time that they had for themselves and the freedom that accompanied it.

Shannon: And your husband has passed away?

Winnifred: Yeah, 8 years.

Shannon: Do you feel like you're managing OK with that?

Winnifred: Yeah, because he was not the kind of person who did things for me, you know. He didn't. I had to do for him. He was like a child. So I don't miss

him. I don't wish that he was dead. And as far as men are concerned in my life, I like being by myself. I don't object to being alone. I'm going to get a little sofa with lots of pillows and plants in the corner. Do sculpture, and time passes by. What do you need someone to pest you?

Shannon: Absolutely.

Winnifred: If I found someone who had the same things that I like. But even so I wouldn't move in with anyone or anyone move in with me. I like my privacy. Like one girl says "Oh we could rent a room together, it would be cheaper" I say "No, I like to be by myself", I really do. (interview, December 1, 2003)

Time spent alone was not viewed negatively by any of the participants. Having the freedom and the ability to partake in the activities that they chose, whether it was alone or in a group, was empowering for these individuals and gave them a sense of control over their lives.

4.8 Social Support

Social support played a significant role in the success of the participants as they moved back into the community. This support existed while they were in the hospital as well as when they were living back at home in the community after discharge. Support from family members was most prominent while support from friends was more peripheral. The participants did not speak of any strong friendships that were particularly helpful in the transition. It became apparent that the social networks of the participants were small in size and that close friendships were rare. Friends were not key contributors of social support.

Shannon: Do you have a lot of friends that you talk to?

Kathy: No, they're more seniors. They have the same condition as me or even worse.

Shannon: Do you wish that you had more chance for this?
Kathy: No, no. I have no patience.
Shannon: You have no patience for it?
Kathy: No.
Shannon: How come?
Kathy: Because some people tell me about their problems and I have my own. So I don't like the small talk. (interview, November 28, 2003)

Friends, however, did seem to provide companionship and acted mainly as a venue for leisure activities.

Shannon: Have your friends been helpful to you as you've been dealing with your depression?
Winnifred: Yeah.
Shannon: In what way?
Winnifred: Well, they pick me up and take me out.
Shannon: Do they bolster your mood a little bit?
Winnifred: Yeah. I have a friend, she likes to go out to movies. But I can't afford to go to the movies and dinner. That's expensive. So I don't see her too much. (interview, December 1, 2003)

As well, the participants were often surprised at the fact that their friends had provided any amount of support to them through the process of community integration. The participants seemed to expect to experience stigma or alienation from their friends. When this stigma didn't come to fruition, these friends actually exceeded the participants' expectations.

Henry: I never dreamed or knew that people would support you. You know what I mean? Because it's the first time and I've never been in the hospital before. I'm so surprised. (interview, February 25, 2004)

As illustrated above, support from friends was appreciated by the participants but they didn't place great emphasis on these relationships. Family played a much stronger role in the community integration process. All of the

participants had supportive relationships with at least one family member. The participants spoke very highly of these family members, stating that their families had been even more supportive than the participants ever expected they would be.

Penny: I don't have any other services I rely on. I just have my family. Just..It's a big thing. They really come through. I never expected them to come through like that. (interview, December 3, 2003)

Family members were present and supportive during the hospitalization and throughout the community integration process. The participants relied on their families heavily and attributed much of their success to the relationships that they had with their family members.

This family support came in many forms, from cooking meals and looking after bill payments to providing emotional support throughout the mental health ordeal.

Shannon: You mentioned you had a daughter?
Winnifred: Yes, she lives in the United States.
Shannon: Do you talk to her at all?
Winnifred: Every day, every day. Oh, my phone bill (laughs).
Shannon: When you say you would like to go there more often, is that because you would like to go to the States or because you would like to spend time with your daughter?
Winnifred: Yeah, because I want to spend time with my daughter. I spend all my time with her [when I visit] unless she's busy. But I stay with her all the time. (interview, December 1, 2003)

Social support from family members was a strong facilitator of community integration for the participants in this study. This support far exceeded the expectations that these individuals had of their families. The

ability to provide emotional support throughout the process was invaluable but physical proximity also played a role. Even if family members lived a considerable distance away, their ability to be physically present and assist in the transition from hospital to the community provided the participants with peace of mind and a sense of security throughout the process.

4.9 Burden

Although the participants were greatly appreciative of social support from family, at the same time, they were extremely protective of their family members. Placing undue burden on their family members was a huge concern for these participants. This became most evident when four out of five of the participants refused to allow me to contact their family member for this study. All four of these participants voiced concern that their family members were already too busy and under too much stress. The participants did not want to impose any extra stress on their families, indicating that they had already given more time than expected.

Shannon: Are you sure? It would be very helpful to me if I could speak with her.

Kathy: No. I can't take her time. She is working and has obligations at home. No. (interview, November 28, 2003)

Before I even had a chance to ask permission to contact Ruth's daughter, she refused, stating:

Ruth: Yes. Because she was afraid of how I would handle things. It took a while for me to convince her. When she came here on a visit was when she really did realize that I was dealing with things properly. I was cooking for myself. When she came, she brought me a whole lot of kosher food,

ready-made stuff to put in my freezer, plus kosher meat to cook. So I really want to make sure I'm not a burden to her. For that reason, you had in your letter about contacting someone close to me. Right now she's under pressure to get some work done on her thesis. I don't think it would be a good time. (interview, March 1, 2004)

The participants seemed to work extremely hard at recovery so that their families would not have to worry about them. This was apparent, not only when I asked permission to contact their family members, but throughout the interviews.

Shannon: Have you ever thought about moving out west to be closer to your daughter?

Ruth: I don't want to be an impediment to her. It would just mean she would have to worry about me being alone. I know my way around here and I have everything that I need here. To start again over there would just mean I would be a burden on her. That's the last thing I want to do. We communicate very well now. I've put it down as one of my major priorities, her state of mind. As long as she's happy, I'm happy. If she's healthy, I'm happy. I can manage. (interview, March 1, 2004)

Close, supportive relationships with family members were highly valued among the participants. These relationships were held in such high regard that the participants went to great lengths to ensure that nothing happened to compromise these relationships. They appeared strongly motivated to remain in good mental health in order to avoid imparting any further burden on their family members.

4.10 Being Healthy

The concept of health, mainly physical, but also psychological, played a key role in the lives of these individuals and in their community integration. They not only had to deal with their mental health issues, but also needed to cope with the variety of physical issues and challenges that they faced as they aged. Henry, for example, developed Bell's Palsy shortly after being discharged from the hospital. He described its impact, saying:

But my eye, that's why I keep my glasses. When I walk out in the morning to go for coffee, I put like this [puts his glasses on] so not much cold air comes because it makes it drip. It's not cured yet. (interview, February 25, 2004)

Physical health not only impacted the day-to-day functioning of these individuals. It could also influence the individual's mental health and their ability to cope with their psychiatric issues. Kathy was experiencing a great deal of pain due to arthritis and, consequently, having trouble sleeping at night.

Shannon: Is there anything else that you think would make it easier for you here at home?

Kathy: No. I only have one wish – to sleep during the night. I can't sleep without the sleeping pill. Last night, I was sleeping about 6 or 7 hours and today, I am human. I can talk with you. Day before, I took the sleeping pill but I couldn't sleep. I didn't sleep all night. What I need? I need sleep. But I need sleeping pills for sleeping so I can communicate. If I am not sleeping, I can't communicate. (interview, November 28, 2003)

There were many examples like this where physical well-being had a profound effect on the mental health of these individuals. The reverse, however, was also apparent. Coping with a mental health issue could negatively impact an individual's physical health.

Penny: ...So it's harder for me now to make dinner or serve dinner to people.

Shannon: Why is it harder?

Penny: Why? I just feel tired.

Shannon: More tired than when you were feeling well before going to the hospital?

Penny: Yep. I don't know. They seem to think it's from the meds.

Shannon: How do you find your motivation to do things now?

Penny: Well, I've never missed a class. I'm very motivated to go, even if it's difficult to go. It just depends about making plans or not making plans because of how I'm feeling that particular day. Before I could stay out all day you know, go to the library, do things. Now I just don't feel I can. (interview, December 3, 2003)

Despite the challenges of coping with a multitude of health issues, the participants maintained a sense of optimism and were able to put their health issues into perspective. For example, although Henry stated that he still did not feel “100 percent, only about 90 percent” (interview, February 25, 2004), he was able to speak positively about his issues.

Henry: First, now I sleep a little better. Not (pause), I don't sleep 100 percent. But lots of people, reading the newspapers, they have sleeping problems in this country.

Shannon: Absolutely. Me too.

Henry: But I improved a little bit. Second, the system [points at stomach] works a little better now because I eat more food. Before, I couldn't eat. Thirdly, physically, I'm just a little bit stronger. I feel it in my legs, I can walk. (interview, February 25, 2004)

Multiple health issues were certainly a challenge to these individuals. In coping with these health issues, however, the participants were able to take control of how these health issues impacted their lives and their community

integration. Knowledge about health was an important and related tool used by these individuals in managing their health and will be discussed in the following section.

4.11 The Power of Knowledge

Having knowledge was strongly equated with having power to deal with mental health issues. Two types of knowledge were most apparent: knowledge about signs and symptoms of mental health issues and knowledge about ways to manage these signs and symptoms and function optimally in the community.

By having knowledge about the signs and symptoms of their mental health issues, the participants felt that they were empowered to prevent such extreme manifestations of the disorder. They believed that if they could recognize the early signs of mental deterioration, they could seek treatment in the community at a much earlier time, thus hopefully preventing another hospitalization.

Shannon: So then, just to finish, are there any suggestions you would have for people as they're going through the same process as you about things that might help them or things they might have to deal with?

Henry: The only thing...if I knew what depression is 7, 8 years ago. The first thing I should ask the doctor to do is to put me in the hospital here and get treatment. But I let it go so long and that's why I became so bad. If I knew I was depressed before, maybe they gave me some pills or put me here for a week...

Shannon: It might not have been so bad?

Henry: That's right. That's why I suggest to people. If I see someone having problems concentrating or having problems sleeping, I'm going to tell them to go to the hospital and see the doctor. Because

now I know what depression is, what you go through.

Shannon: *So knowing some of the signs and symptoms ahead of time would have helped you to maybe not get as bad as you had, eh?*

Henry: *Yeah.*

Shannon: *That's a good point.*

Henry: *I didn't know anything about depressing, I didn't know anybody [with depression]. I was 55, 60 years old, I didn't know what depression means.*

Shannon: *Did you talk about it at all with your family doctor?*

Henry: *I went to my family doctor, I told him I couldn't sleep at night. So he gave me this medicine. I couldn't sleep. Possibly I was too depressed to sleep. But he didn't find out I was depressed. And when he realized I was depressed, it was too late. So he sent me here. (interview, February 25, 2004)*

Knowledge about ways to manage mental health issues was also empowering for the participants. This knowledge helped them to take control over their illness and facilitated strategies for avoiding future hospitalizations.

Ruth: *I'm trying to change my mental habits and be not too demanding, to lower my standards a bit. I'm more reconciled to the fact that I'm retired and I'm not worrying so much about my problems. There's a lot to interest me.*

Shannon: *You've become more accepting of things like that?*

Ruth: *Yes.*

Shannon: *You said there's more to interest you?*

Ruth: *There's a lot that interests me. If I can keep a decent balance between activities and time for myself. Because it does frustrate me when I can't get things done. (interview, March 1, 2004)*

Staying healthy and avoiding future hospitalizations was major focus for these individuals. Knowledge was a powerful strategy used to address this concern. Possessing the knowledge and being able to prevent major

manifestations of mental health issues was empowering and provided these individuals with a sense of control over their own destiny.

4.12 Smooth Transition

The gradual transition home from the inpatient unit was another important factor in preventing relapse and readmission to hospital. Moving back home into the community from the hospital was a gradual transition for all of the participants. They all began to spend short times at home long before they were actually discharged from the hospital. The process began with spending a few hours or a day at home and gradually expanded to full weekend passes. All of the participants indicated that this was extremely helpful and allowed them to gradually get back into their routine at home, instead of being abruptly discharged from the hospital.

Shannon: I just wanted to clarify about going home on some weekends before you left here. Did you feel it was helpful to go back home a little bit at a time instead of maybe going cold turkey and moving back home?

Ruth: Yes, it was definitely helpful. In fact it worked out to my advantage because I had to get my bills sent back to me. My daughter was handling my finances. Then I was able to deal with a few things at home. Sometimes I would make it a longer weekend and stay on a Monday so I could get some things done before I got back.

Shannon: That you couldn't get done on the weekend?

Ruth: That I needed a working day to do. (interview, March 1, 2004)

The transition also involved linking these individuals with outpatient supports prior to their discharge from the inpatient unit. The participants spoke

highly of this aspect of their discharge, noting that they had not experienced this aspect of the planning at other facilities.

Shannon: OK, so you were saying about a couple of different phases [of the transition back home from the hospital].

Penny: I guess the first phase was when they [staff] became aware that I could leave the hospital. First they gave, very briefly, I could go away for lunch. And then I could go for the day, and then I went to the lake for a weekend.

Shannon: Oh, you did?

Penny: So each time there was an increase. Then they started planning for discharge into a group that meets every day, four times a week.

Shannon: Was that the day hospital?

Penny: The day hospital, yes. So that's where I am now. I'm just finishing off my 4 months in that day hospital. And living my normal life this way. I think it's a very well planned program because they take the time to think of what a person can handle and what will be next. For instance, just in going from the hospital to the day hospital, I was in 2 places at once. I slept in the hospital and had my meals there but all the activities I did in the day hospital so I could get to know the people. Now that is unusual, that kind of treatment. (interview, December 3, 2003)

As the participants progressed during their stay on the inpatient unit, their outlook about the unit and their readiness to leave changed dramatically. Henry spoke very candidly about his experience as an inpatient, a very positive one in the beginning:

Shannon: How did you find the experience of being in the hospital?

Henry: I tell you, it helped me so I liked it. (interview, February 25, 2004)

Later on in his stay, he was quite ready to go home:

They told me if I wanted to stay more, I could stay there. But I said no. When I got a little bit better here, I felt like I was in jail. Like, you know, I had to go out all the time. I would go down to the cafeteria, have coffee. I didn't feel very, very comfortable after in the hospital. You know what I mean? I wanted to go out. (interview, February 25, 2004)

Penny explained her progress while in the hospital:

Penny: You know, a funny thing happens to you. I had a definite break in my feelings in the hospital. First I wanted to be confined to my room and I didn't go to any of the classes or anything. Then gradually I started going and I realized in a way that that's a measure of health. I never knew that. And that's how staff was measuring how I was doing. What was the question you asked?

Shannon: Were there things we could have done better or more things that we could have helped you?

Penny: Oh no, but the idea of what I figured out I was ready. Everyone had begun to say, "Oh gee, don't you look good" "You're not the same person who was here 10 days ago". I started getting better. I couldn't read at all. I started reading. Then I knew I was getting better. Then when we decided on an exit date. I was quite ready to go. And I had become friendly with the whole group there too. But I didn't want to prolong it anymore. I was ready to go. (interview, December 3, 2003)

It was important to the participants that the staff at the hospital were understanding of their readiness to leave the hospital. The gradual transition process was extremely successful and facilitated a much less stressful move back into the community.

4.13 Preliminary Conclusions

This chapter has provided an in-depth analysis of the main themes that emerged from the data gathered from the five older adults who participated in

this study. Independence emerged strongly as the central theme and was reflected in many of the other concepts discussed. Social support and feelings of self-worth and productivity facilitated community integration, inclusion, and independence. Knowledge of ways to prevent further mental health events was also a powerful contributor to feelings of independence and empowerment. Physical health issues challenged the participants' independence but utilizing successful coping strategies facilitated feelings of empowerment. A smooth, gradual transition from the hospital back to the community also positively influenced community integration and independence. Concern over burdening family members was a strong motivator to maintain health. Stress was another constraint faced by the participants but, like physical health issues, the utilization of successful coping methods to manage stress facilitated feelings of control and independence among the older adults. These meanings and the relationships among these findings will be discussed in detail in Chapter 5.

CHAPTER 5: DISCUSSION & SYNTHESIS

5.1 Introduction

The older adults who participated in this study provided me with a rich and detailed description of their experiences with community integration. Their stories focused on the central theme of independence. A number of related themes emerged that highlighted constraints that the older adults had experienced in the process as well as facilitators that helped them achieve integration and inclusion in their communities. Despite facing numerous constraints to independence and community integration, these individuals consistently reported strategies that they used to manage the many challenges that they faced on a day-to-day basis.

The concepts of independence, recovery, empowerment, inclusion, and community integration were intimately linked and intertwined in the stories of the older adults. A number of the themes that emerged from the data were closely tied to feelings of empowerment and the process of recovery. The experience of independence, as described by these individuals, evoked feelings of empowerment and was strongly associated with the concept of recovery. For these older adults, being healthy, and thus, independent, meant being integrated. Their extent of community integration, inclusion, and citizen participation, however, was somewhat divergent from many of the traditional theories and definitions of integration.

The following chapter will provide a detailed discussion of the concept of independence, as expressed through the lived experiences of the participants.

The remaining themes, outlined in Chapter 4, will be examined in relation to constraints and facilitators to independence. The relationship between independence, recovery, empowerment, inclusion, and integration will be explored in detail and compared to current literature. Following these discussions, the emerging theory will be presented, bringing all of these themes together to illustrate the experience of community integration as described by the older adults in this study.

5.2 Independence

Independence and dependence are concepts frequently examined within the context of aging and disability. A sense of independence has been found to play a vital role in both physical and psychological health (Rodin, Timko & Harris, 1985). Feelings of control and freedom are important aspects in the lives of older adults (Baltes & Baltes, 1990). These and other factors such as health and family support have been shown to contribute to the ability of older adults to remain living in the community (Mack, Salmoni, Viverais-Dressler, Porter, & Garg, 1997).

Despite the obvious need to understand the role that independence plays in the lives of older adults with mental health issues, little attention has been paid to understanding the concept of independence from the perspective of the older adults themselves. The findings from this study help to illustrate the meaning and value given to independence by the older adults.

The concept of independence discussed by the older adults in this study differs somewhat from the definitions of independence commonly used in North

American society. Independence, from the perspective of a vulnerable population such as older adults with mental health issues, is quite different from the concept of independence within the general population. Despite the frequent use of the terms independence and dependence in the literature, they are rarely defined explicitly. Instead, they are used with the assumption that their meanings are clearly understood and universally accepted (Cott & Gignac, 1999). Independent, according to Webster's dictionary, is defined as "not dependent, not subject to control by others" and "not requiring or relying on something else" (Merriam-Webster, 1991). The concepts of autonomy and individualism remain the guiding principles in bioethical theory, focusing on a complete state of self-reliance (Clark, 1991). The North American view of rugged individualism and non-reliance on others is incongruent with the idea of independence shared by individuals with disabilities. Instead of defining independence as the absence of dependence on others, research from the areas of sociology and gerontology focuses on psychosocial variables such as attitudes, social support, and economical, political, and social environments (Williams, 1991).

For the older adults who participated in this study, independence did not signify the absence of dependence. According to the traditional view of dependence and independence, they were dependent in many aspects of their lives. They needed medication to maintain their mental health, they relied on others for transportation, and they benefited from emotional and physical support from their families. Yet each of these individuals adamantly maintained

that they were independent, using the word repeatedly throughout their interviews. Independence had a unique meaning for these individuals. They perceived freedom and control in their lives.

Kathy: Yes, the best thing for me is to stay home and do what I want. If Nancy [caregiver] is doing something that I don't like, I am telling her: "Nancy, do it like this because I don't like it that way". So I am independent. In my way, I am independent. (interview, November 28, 2003)

Although the literature fails to address the issue of independence for older adults with mental health issues, a number of gerontological studies have examined these concepts from the perspective of older adults with chronic physical disabilities, such as osteoporosis, osteoarthritis, and chronic obstructive pulmonary disease (Boerner, 2004; Falter, Cott & Gignac, 1999; Gignac & Cott, 1998; Gignac, & Cott, 2003; Gignac, Cott, & Badley, 2000). Like mental illness, these are incurable, chronic disorders that many older adults are faced with as they age. These studies have shown that older adults do not adhere to the principles of autonomy and individualism in relation to independence. Instead, like the participants in this study, they often accept a certain degree of dependence in order to prevent or avoid future pain and disability or to leave themselves with the time and energy to focus on other tasks (Gignac & Cott, 1998).

Each of the participants in this study had a unique life experience that they shared with me. When these individuals spoke about being independent, I was

slightly taken aback, given the variety of physical and emotional challenges that they still continued to face.

Shannon: When they spoke of being “independent”, I had to ask them to clarify what they meant. I was conceptualizing and measuring independence in a very medical way, thinking about activities of daily living and the amount of support that these individuals needed in order to continue to live at home. It was the passion with which they spoke of independence that helped me to realize how important and real this idea was to them. Regardless of their issues and challenges, they truly felt independent and in control of their lives. (reflexive journal, March 4, 2004)

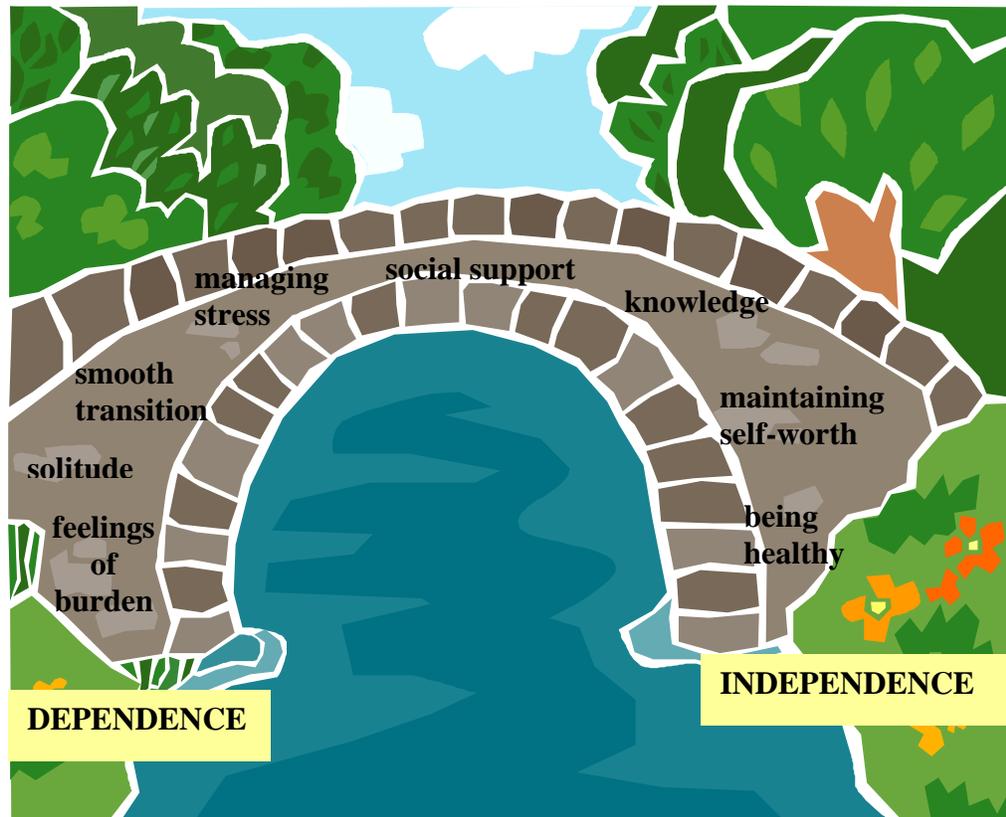
Although their situations were very individual, they shared a number of common issues and strategies for managing these issues. The strongest bond within the stories of these older adults was their strong sense of independence and their commitment to staying healthy in order to maintain this independence. Their ability to adapt to their environment and to its inherent challenges was the real measure of independence for these older adults.

The journey from dependence to independence was a process of constant evolution and adaptation for the older adults. Facing and adapting to the challenges throughout this journey resulted in a strong sense of independence, achievement, and consequently, empowerment. By making use of available resources as facilitators to community integration, and by implementing strategies to manage constraints to the process, these older adults were empowered and able to be successful in their quest for community integration.

Figure 3 illustrates the relationship between independence and dependence and the factors described by the participants that contributed either positively or

negatively to their experience of independence in the community. Section 5.3 will outline some of the strategies implemented by these individuals to cope with the challenges that they faced in the community reintegration process.

Figure 3: Bridging the Gap between Dependence and Independence



5.3 Constraints and Facilitators

The participants spoke of a number of issues that arose which challenged their independence and their mental health. These were evident in the themes discussed in Chapter 4 and included:

- Physical health problems
- Feelings of burden
- Stress

These issues can be categorized as constraints to the independence of the participants. As noted in Chapter 2, barriers can be viewed as obstacles that individuals experience in their pursuit of a goal. A constraint may result from the barrier and may intervene in the process and affect the individual's ability to achieve a particular goal (Crawford & Godbey, 1987). For these participants, the constraints were mainly intrapersonal and structural in nature.

Intrapersonal constraints come from within the individual and involve psychological states and attributes (e.g., stress, depression, anxiety, and perceived skill) (Crawford & Godbey, 1987). These constraints may affect an individual's preferences and consequently his/her behaviour in relation to such preferences. Stress and feelings of burden were two intrapersonal constraints encountered by the older adults in this study. They experienced stress when their environment was overstimulating, as illustrated in Henry's comments:

Henry: I can't come up to this joy. Something inside me tells me "Do not laugh".

Shannon: Really. Is that different from before?

Henry: No, it's been from before and hasn't recovered yet.

Shannon: So you sort of lost your sense of humour?

Henry: Yes.

Shannon: And why do you think that is?

Henry: I don't know. That's what I asked all the doctors. It hasn't come back, my humour, my joy. See, that's the problem. This problem, it's inside you that makes you bring up joy, laugh, happiness. You know what I mean?

Shannon: Yes. Do you still feel comfortable around other people?

Henry: Yes, I feel very comfortable. Yes, but after a bit I get tired. I want to be quiet. There's two problems now. My head sometimes doesn't take too much noise, that's one problem, and my joy, my happiness that's it. (interview, February 25, 2004)

Being a burden on their families was a significant concern for the older adults. Although all of the participants had supportive family relationships, they were extremely protective of their family members. These relationships were held in such high regard that the participants went to great lengths to ensure that nothing happened to compromise these relationships. The concern about caregiver burden is a valid one. Caregivers often experience a significant amount of stress when caring for a loved one who is experiencing some type of health problem (Dupuis & Pedlar, 1995; Laidlaw, Coverdale, Falloon, & Kydd, 2002; Veltman et al., 2002). Caregivers, however, also experience positive benefits related to the caregiving experience, including the development of strong relationships and a sense of connectedness with their family members (Dupuis, 2000). Consistent with these findings, the older adults in this study spoke highly of their relationships with their family members, indicating that these relationships were extremely helpful in the process of community integration.

Although this concern about being a burden was stressful for the older adults, they made use of negotiation strategies discussed below and transformed a stressful situation into a motivational one. They appeared strongly motivated

to maintain their independence, remain in good mental health, and prevent relapse in order to avoid imposing any further burden on their family members.

Physical health issues represented the most significant constraint faced by these older adults. They not only had their mental health to contend with but also a multitude of physical issues as well.

Kathy: In August. I was home for a month when this happened, when I fell down again. And I have to go again to the hospital.

Shannon: OK, so you were home [from the hospital] for about a month, then you fell, and that's when you went to [the other hospital], right? And how long did you stay there, at [the other hospital]?

Kathy: For 5 weeks, no 4 weeks.

Shannon: OK, so you've been actually living here at home since about when?

Kathy: When I came from [the other hospital], in October. About 2 months already here.

Shannon: OK, just so I have an idea how long it's been. Can you tell me a little bit about what it was like for you when you left the hospital?

Kathy: I was very satisfied because it was successful for me. I didn't buy the walker when I left the hospital because I was sure of myself, nothing was going to happen to me. Of course, I have pain in my back constantly for already a few years. I'm constantly in pain. Walking and sitting and sometimes even lying down. But this was the time when I could walk without the walker.

Shannon: Kathy, what is the pain in your back from? Is it arthritis?

Kathy: Yes, rheumatoid arthritis. And there's damage, probably from driving the car. My left leg was always working because I drive with both legs.

Shannon: OK. So that has caused some pain in your back, from your driving?

Kathy: Yes, maybe from this I was damaged.

Shannon: So when you went into [the hospital], were you feeling depressed about all the pain?

Kathy: Yes, yes.

Shannon: Was that your only problem you were having or were there other things at the time?

Kathy: I was depressed because of the pain in my back.
Shannon: OK. And you feel that the medication that you got at [the hospital] helped you to feel better?
Kathy: Yes, I got better.
Shannon: Now, I'm also wondering...you said you were feeling pretty good when you were discharged.
Kathy: Yes.
Shannon: Were you looking forward to coming home?
Kathy: Yes, of course. My daughter prepared me the company, and I was ready to come home. But I couldn't stay alone because I have a broken hand.
Shannon: You broke your hand?
Kathy: Yes, last year, 1st of April. I went to clean my car because it was such a snowy day and I fell down and I broke this [points to arm] on this side so I can't lift, I can't drive anymore. This was part of the depression, too. Because I couldn't drive and with the addition of the back [pain] which was so many years already. (interview, November 28, 2003)

Despite facing many challenges to their overall feelings of wellness, these older adults took ownership of these challenges and took pride in being able to negotiate the constraints and facilitate independence. Brandstadter and Rothermund (2002) developed a framework that outlined two ways in which individuals negotiate conflicting demands as they age. The model “distinguishes two modes of reducing discrepancies between desired and factual situations or developmental outcomes” (Brandstadter & Rothermund, 2002, p. 117). Throughout the life span, but particularly in later life, individuals need to establish a balance between their current life situation and the life paths that were desired but were never accomplished. Brandstadter and Rothermund (2002) outline two modes of coping with these discrepancies: assimilative and accommodative. In assimilative coping, individuals strive to modify the actual

situation to attain a closer fit with personal goals and projects. In accommodative coping, individuals adjust their goals and actions to fit with the current situation.

In the current study, the older adults used a more accommodative mode of coping with life events. They tended to accept the current challenges, barriers, and constraints with which they were faced. They actively modified their behaviours and their goals in order to avoid the stress that accompanied the discrepancy. A positive reappraisal of the situation often occurred and the individuals refocused their resources on more attainable goals.

- Ruth: I know that a lot depends on my own mental habits. I'm trying to change my mental habits and be not too demanding, lower my standards a bit. I'm more reconciled to the fact that I'm retired and I'm not worrying so much about my problems. There's a lot to interest me.*
- Shannon: You've become more accepting of things like that?*
- Ruth: Yes.*
- Shannon: You said there's more to interest you?*
- Ruth: There's a lot that interests me. If I can keep a decent balance between activities and time for myself. Because it does frustrate me when I don't get things done. (interview, March 1, 2004)*

Although assimilative coping was used to a lesser degree by the older adults, it was a useful approach to managing certain stressful situations. The older adults sometimes adapted their behaviours and choices in order to cope with certain constraints. Involvement in solitary activities, for example, allowed the older adults to continue to participate in leisure activities without experiencing the stress that accompanied group leisure activities. In this way, solitude, as discussed in Chapter 4, was not a constraint to community

integration but rather a means of coping with the stress that was seen to accompany group activities. Previous research supports this type of replacement of activities (Duke, Leventhal, Brownlee, & Leventhal, 2002). Older adults who replace previous activities with new activities that better suit their current situation tend to exhibit a more positive affect than those who don't replace their activities at all.

As well as using accommodative and assimilative coping to negotiate their constraints, the older adults in this study also made use of a number of facilitators in order to achieve community integration. Raymore (2002) developed an alternative theory of leisure participation and proposed that individuals may be influenced by facilitators to leisure that encourage or enhance leisure participation. She states that, "the absence of constraints does not necessarily lead to participation" (Raymore, 2002, p. 37). Although this theory pertains specifically to leisure, the concept of facilitators is conceptually relevant to the process of community integration for older adults with mental health issues. Facilitators, as described by Raymore (2002), are viewed as factors that promote the formation of leisure preferences and encourage participation in leisure activities. Although these facilitators may interact with constraints, they should not be viewed simply as the opposite of constraints, but as a separate and distinct concept.

The participants in this study spoke about a number of factors that positively contributed to their community integration. As outlined in Chapter 4, these included:

- Smooth transition from hospital to community
- Knowledge about mental health issues
- Social support
- Maintenance of feelings of self-worth

All of these factors facilitated the older adults' transition from the hospital back into the community. The older adults also indicated that their ability to remain in the community and prevent relapse was positively influenced by these factors. The gradual transition from the hospital back into the community was extremely helpful to these individuals. Involving the older adults in the process of discharge planning allowed them to take ownership of the situation and facilitated feelings of competence and control.

Possessing knowledge about mental illness and ways to prevent relapse was empowering for these older adults. This, too, enhanced feelings of control over the illness and actively involved the older adults in the process of treatment and recovery. For example, Henry stated that he was appreciative of the knowledge that he had gained. He felt that this knowledge would help him to identify the signs and symptoms of depression and allow him to seek treatment before his situation became so dire that he required another hospitalization. (interview, February 25, 2004)

Social support was also identified as a powerful facilitator to independence and community integration. Research has shown that social support can have both positive and negative effects, depending on the nature of the support (Parris Stephens, Kiney, Norris, & Ritchie, 1987). Older adults with

mental health issues benefit greatly from supportive relationships with friends and families, who play a significant role in the lives of their loved ones, often providing them with much needed emotional and instrumental support (Owens & Qualls, 2002). As discussed in Chapter 4, the older adults in this study were involved in positive, supportive relationships with their families. This social support was a strong facilitator of community integration, much stronger than the support received from friends in the community. Family members were valuable resources for the participants. The participants relied heavily on their families and attributed much of their success to the relationships that they had with their family members. These findings were consistent with previous research by McCormick (1999) that revealed a positive relationship between social support and life satisfaction among individuals with persistent mental illness.

Finally, the ability to maintain feelings of self-worth also facilitated independence. Involvement in productive activities such as volunteering has been found to be an integral aspect of healthy aging (Menec, 2003; Rowe & Kahn, 1997). Volunteering, for example, has been shown to enhance feelings of well-being among older adults (Menec, 2003). By feeling engaged and involved in their community, older adults were happier and reported higher levels of life satisfaction. The older adults in this study did not express strong interests in the activity based leisure opportunities that have traditionally been available to older adults. Instead, they were passionate about opportunities for continued learning and education in the form of writing courses, computer courses, and guest

speakers. Volunteering was another activity that evoked feelings of productivity and a sense of achievement. Maintaining a sense of self-worth was an important facilitator to independence, which not surprisingly perhaps, had a positive effect on the self-esteem of the older adults.

5.4 Recovery

As discussed at the beginning of this chapter, the concept of independence appears to be quite different for individuals with disabilities, including older adults with mental health issues. According to the traditional view of dependence and independence, the older adults who participated in this study were dependent in many aspects of their lives. For these older adults, independence did not signify the absence of dependence. Instead, independence was related to being in control of their lives, including their health, relationships, and leisure.

If we are to understand the concept of independence for older adults with mental health issues, it is useful to examine the concept of recovery. This concept is well documented in the mental health literature and can be defined most simply as “a subjective experience of regaining control over one’s life” (Allott, Loganathan, & Fulford, 2002). Recovery, like independence, is not merely the absence of symptoms or a return to previous levels of functioning. Rather, it is a process, a way of life, an attitude, and a way to approach the day’s challenges (Deegan, 1988). It does not require a cure, but instead is “a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness” (Anthony, 1993, p. 15).

The older adults in this study conceptualized independence in very much the same way as the literature describes the process of recovery. Recovery, for these older adults, meant being independent, not in the traditional sense of the word, but in regard to having control over their daily functioning. They did not necessarily return to their pre-hospitalization levels of functioning, citing physical and emotional issues such as headaches, decreased energy levels, and a lack of joy in their lives. Instead, recovery meant being able to function independently in their homes in the community and to have the freedom and control to make choices and decisions about their daily lives. Although the participants in this study spoke specifically about independence, this concept is clearly aligned with the idea of recovery as outlined in the mental health literature (Allott et al., 2002; Carling, 1995; Nelson, et al., 2001).

Being healthy was a key theme in the recovery process for the older adults in this study. They felt that as long as they could remain in good health, they could continue to live independently in their communities. They viewed health as a strong indicator of independence and they appeared strongly motivated to remain in good mental health in order to avoid relapse and to minimize any further burden on their family members.

The importance of being healthy is well documented in the literature related to older adults with chronic physical disabilities (Mack et al, 1997; Wolinsky, Wyrwich, Babu, Kroenke, & Tierney, 2003). It has been conceptualized as a multidimensional, context dependent concept that is highly subjective in nature (Wolinsky et al., 2003). Being well is strongly situationally dependent and

individual perceptions of health vary significantly from one individual to the next. Both physical and psychological well-being are interdependent and can have a strong influence on feelings of control and mastery (Mack et al., 1997). The findings from this study support previous research with older adults in which health was seen as one of the most important contributing factors to being able to live independently in the community (Mack et al., 1997). Being and staying healthy, both physically and psychologically, was an essential aspect in the recovery process for the older adults in this study. It was strongly equated with feelings of independence and empowerment, and made a significant contribution to community integration for these individuals.

Having the ability to face the day's challenges, utilize facilitators, assimilate or accommodate constraints, and continue to function in a meaningful way was the underlying experience of recovery for these older adults. This experience of recovery facilitated feelings of independence for these individuals and allowed them to continue to live and achieve integration in their communities.

5.5 Empowerment

Independence and recovery are closely linked to the experience of empowerment. Feelings of independence and successful recovery have been found to promote empowerment in older adults with chronic physical disabilities (Barlow & Williams, 1999). Empowerment is central to the process of community integration and inclusion (Pedlar et al, 1999). Within the community integration literature, the concept of empowerment has received considerable attention. A variety of empowerment theories exist, each

conceptualizing empowerment in slightly different ways. For example, a number of empowerment theories suggest that gaining power over social and political resources is an important aspect of empowerment (Wallerstein, 1992; Rappaport, 1987). According to Rappaport (1987), empowerment “conveys both a psychological sense of personal control or influence and a concern with actual social influence, political power, and legal rights” (p. 121). As well, Zimmerman and Rappaport (1988) view citizen participation as a key contributor to empowerment, whereby individuals who exhibit a greater amount of citizen participation also experience greater levels of empowerment.

Other empowerment theories have less of a political emphasis and focus on the concepts of choice and control, viewing empowerment on more of a personal level. Empowerment has been defined as “opportunities for, and conditions that, promote choice and control, community integration, as well as valued resources” (Nelson et al., 2001, p. 127). Hastie and Pedlar (1993) describe empowerment as a process in which individuals move from being dependent and powerless to having control over their own affairs. Key elements in the empowerment process are the notions of choice and control, as well as the importance of individuals’ perceptions of the distribution of power in their communities.

For the older adults who participated in this study, empowerment had little relation to political influence or citizen participation. These individuals were not extremely active within their communities nor did they aspire to make significant changes there. For them, empowerment meant having control over decisions that affected their daily lives. These older adults strongly equated

empowerment with being healthy and independent and with the ability to maintain what they perceived as an acceptable quality of life. Their perceptions fell more in line with Lord and Hutchison's (1993) definition of empowerment as a process whereby "individuals achieve increasing control of various aspects of their lives and participate in community life with dignity" (p. 7).

Being independent, as described in Section 5.2, was associated with feelings of control and mastery, even when the older adults relied on their families for support. Needing support from others did not, in the minds of these older adults, mean that they were dependent or less empowered. They were in control of their lives and they used these supports to enhance their independence. This supports previous research conducted with older adults with chronic physical disabilities. This research showed that older adults actively utilized supports in their communities in order to continue to live independently. This process actually enhanced feelings of choice, control and self-direction for the older adults because they were in control of the decisions that were affecting their daily lives (Gignac & Cott, 1998). Empowerment, in the lives of the older adults in this study, still existed, even when these individuals required support and assistance from others in their communities.

The concept of empowerment was also evident in the participants' discussions related to the power of knowledge. In educating themselves about mental illness, these older adults took control over their illness and became empowered to take action against future relapse and hospitalizations.

Empowerment is a process which can have a powerful impact on individuals with mental health issues and the challenge of community integration. Empowerment has been associated with increased self-confidence and self-esteem, enhanced formal and informal supports, as well as stronger feelings of control and independence (Nelson et al., 2001). In this study, it was directly related to staying healthy and being independent in the community.

5.6 Community Integration

Certainly, older adults have the right to full community participation (Midwinter, 1992) and empowerment has been found to facilitate this process (Nelson et al., 2001). Some researchers have described community integration and inclusion as synonymous with community living, where citizens participate in and contribute to every aspect of community life (Townsend & Ryan, 1991). Older adults with mental health issues should be afforded the same rights as individuals without disabilities with regard to participation in their communities. This idea has been driven to a considerable degree by the principle of normalization. Normalization, as outlined in Chapter 2, has been defined as the “use of culturally normative means to offer persons life conditions at least as good as that of average citizens, and to as much as possible enhance or support their behaviour, appearances, experiences, status, and reputation” (Wolfensberger, 1980, p. 8). Individuals with mental health issues have indicated that they had a strong desire for normalization and wanted to be able to participate in regular opportunities in the community without being labeled according to their disability (Hastie & Pedlar, 1993).

The concept of inclusion plays a central role in the community integration of older adults with mental health issues. Social inclusion involves not only the attainment of rights and power within the community, but more importantly the full participation in families, communities, and society (Labonte, 2004). Individuals with mental health issues must have control over their decisions related to community involvement as well as the care and support that they receive in the community (Basnett, 2001). We must ensure that we are not simply promoting institutionalization within the community by providing services over which these individuals have little control or decision-making ability. Inclusion relies strongly on the principle of empowerment and community (Pedlar et al, 1999), whereby individuals gain control and become empowered to participate fully in their communities.

Consistent with this earlier research, the older adults who participated in this study wanted the right to full inclusion and community participation. This did not mean, however, that they wanted to fully participate in every aspect of their communities. These older adults were very selective about the activities and community groups in which they chose to participate. As outlined in Section 5.3, these individuals modified their activity choices in order to facilitate independence and to prevent relapse. They tended to choose more solitary activities such as reading and watching television, as opposed to more socially oriented group activities.

By choosing more solitary activities, these older adults did not jeopardize the possibility of inclusion or community integration. These individuals made

conscious choices about their welfare and felt in control of their lives. Again, as discussed in Section 5.4, even when these older adults received support in the community, they maintained their feelings of independence and control. Consistent with previous literature, the need for support did not detract from feelings of independence and community integration (Lord & Hutchison, 1993). In fact, the act of receiving social support can be a very positive experience, facilitating social contact and enhancing feelings of mastery by allowing these individuals to complete tasks that may not have otherwise been possible (Baltes, 1995).

The older adults in this study associated community integration with independence, inclusion, recovery, and empowerment. By having the ability to make choices about their level of community involvement, they felt that they were able to achieve successful community integration. Because these older adults were able to continue to live in their homes in the community and maintain their physical and psychological well-being, they felt independent, empowered, included, and, consequently, integrated into their communities.

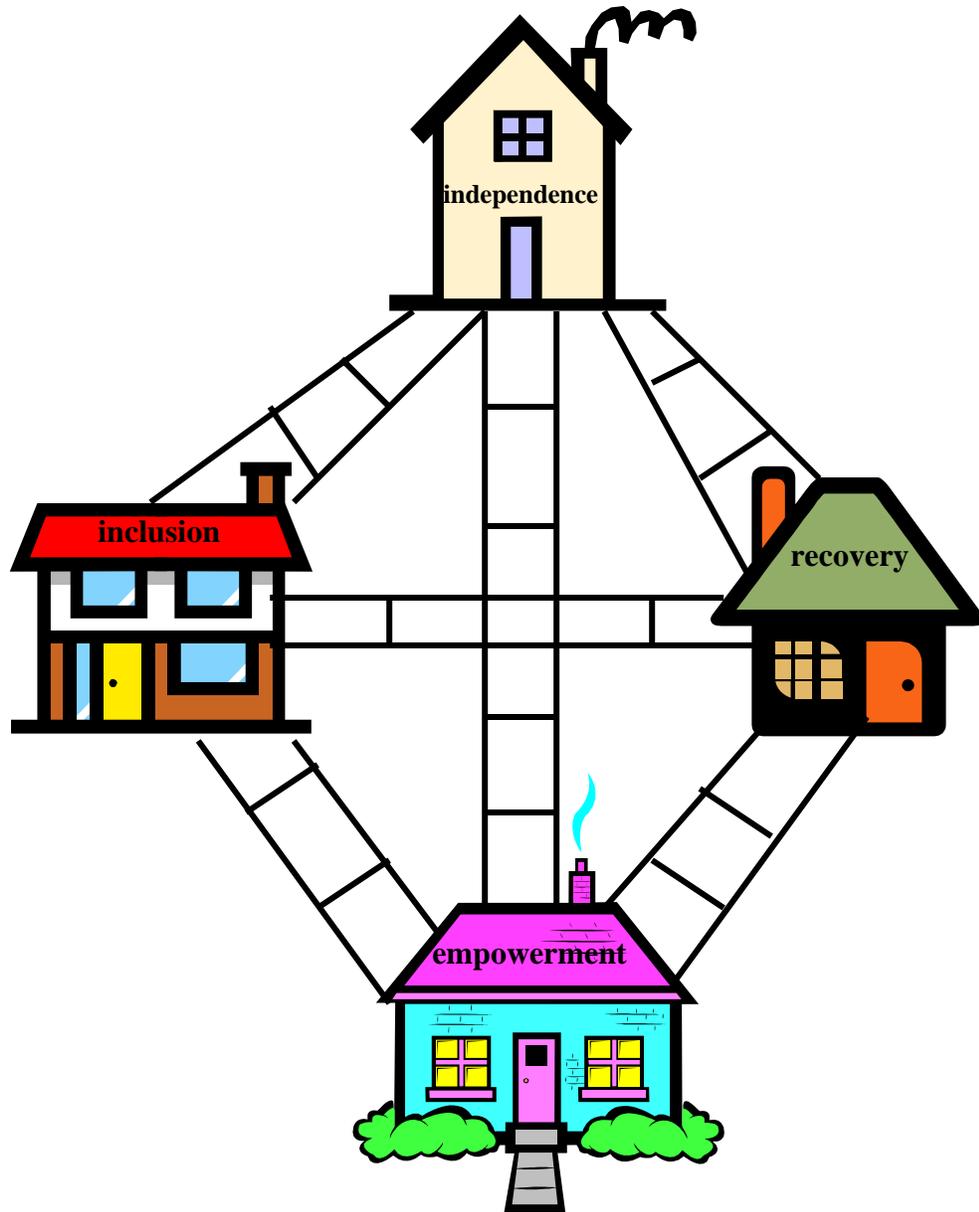
5.7 Emerging Theory

As illustrated in Figure 3 in Section 5.2, the findings suggest that for the older adults, independence was the key factor in successful community integration. Independence represented the ability to control one's life and to minimize dependence on others. Facilitators such as social support, self-worth, being healthy, and a smooth transition assisted the participants in achieving independence. Constraints such as stress, solitude, and feelings of burden were

negotiated, assimilated, or accommodated. These strategies enhanced feelings of control and contributed to feelings of independence, empowerment, recovery, and integration among the participants.

The concepts of independence, recovery, empowerment, and inclusion were intimately linked and intertwined in the stories of community integration of the older adults. The experience of independence, as described by these individuals, evoked feelings of empowerment and was strongly associated with the concept of recovery. For these older adults, being healthy, and thus, independent, meant being integrated. Community integration for these individuals was not strongly associated with social control, political power, or citizen participation. Rather, integration was inherently linked to feelings of independence, inclusion, recovery, and empowerment. Figure 4 illustrates the pathways to community integration for these older adults and reveals the conceptual relationship between inclusion, independence, recovery, and empowerment. This model depicts the importance of these four concepts and the interconnectedness that exists among them for this group of older adults with mental health issues.

Figure 4: Pathways to Community Integration



CHAPTER 6: REFLECTIONS & CONCLUSIONS

6.1 Introduction

Community integration is vital for older adults with mental health issues, both as a process and as an outcome. These individuals have the right to full community membership, participation, and inclusion. The process of community integration is not without challenges and uncertainty. This study developed a thorough understanding of the experience of community integration for five older adults with mental health issues. The information gained from the interviews with these individuals has provided insight into some of the factors that facilitate and hinder the process of community integration. The concept of independence, as outlined in Chapters 4 and 5, was closely linked to feelings of empowerment, inclusion, and recovery, and played a central role in the community integration process for these older adults.

6.2 Reflections on the Research Process

Conducting a qualitative research project is a challenging but immensely rewarding experience. I was privileged to be able to share in the lived experiences of the older adults as they made the successful transition back into their homes in the community. The process was one in which I learned not only about the older adults, but also about myself as a researcher. Having been a Therapeutic Recreationist in the area of mental health, it was extremely enlightening for me to participate with these older adults in the role of the researcher. I quickly became aware of many assumptions that I made as a therapist regarding the independence and motivation of these older adults.

Instead of focusing on mobilizing supports to solve all of the problems faced by the older adults, I was able to listen to their stories and gain a more in-depth understanding of their lives outside of the institutional setting.

Shannon: Once I was able to step out of the role of the therapist and move into the role of the researcher, I truly became able to hear the voices of these individuals. To be able to measure successful integration according to the perspectives of the individuals opened my eyes to a whole new world. It was a world where every minute of every day didn't need to be filled with social or productive activities. The ability to make choices is what it's all about. (reflexive journal, December 6, 2003)

I became immensely aware of the strengths of the older adults and their ability to succeed in their communities without much of the formal supports that we, as health care practitioners, were used to recommending. This experience has forever changed the way in which I approach and interact with clients at the hospital. It has made me more client-centred in my approach and has given me a greater appreciation of the strengths and resiliency possessed by these individuals.

As noted in Chapter 3, each of the five clients who were interviewed was still living at home in the community at the time of their interview. Despite various issues that they were experiencing, they were coping well with their mental health issues and indicated that they were functioning well at home. Consequently, it is important to note that all of the participants in this study generally described very positive experiences of being back home in their community. They all had supportive family members on whom they could rely for social support. None of the participants reported serious financial or housing

issues. The findings from this study, therefore, provide us with insight into the experience of older adults who had been successful in achieving community integration. The results would likely have differed greatly if the participants had included individuals who had not had such positive experiences or who had relapsed and returned to hospital. As well, these individuals volunteered to participate in the research process, possibly contributing to a positive self-selection bias in the sample. Implications of this issue are discussed in Section 6.3.

Finally, the issue of recruitment warrants further discussion at this time. I was unable to recruit any caregivers to participate in this study. As described in Section 3.4, this approach to caregiver recruitment was taken because, in my experience as a Therapeutic Recreationist on this particular unit, clients often indicated that they did not want staff to contact their caregivers directly. The clients preferred to contact the caregivers themselves and the caregivers would then contact the staff on the unit. In four out of five cases, the older adults refused to allow me to contact their caregivers. Consequently, I was unable to obtain any further data on the community integration process from these caregivers. This further emphasizes the concern that the older adults had about being a burden to their family members. Implications for future research are discussed in Section 6.3.

6.3 Recommendations for Research

Research in the area of older adults with mental health issues is extremely limited. Older adults are a growing segment of the population. They represent

individuals with diverse backgrounds who have specific needs and desires as they age. Mental health issues are a significant concern for older adults, yet given the current budget constraints from both the federal and provincial governments, hospital stays for individuals with psychiatric disorders have become increasingly brief (Veltman et al., 2002). These individuals are being discharged back into their communities at a rapid pace. The recidivism rate remains extremely high at approximately 75%, despite efforts to improve the supports within the community for these individuals (Bachrach et al., 1994; Gibson, 1999; Nelson et al., 2001).

Researchers need to critically examine the process of deinstitutionalization specifically related to older adults. As noted in Section 3.5, over an eight month period of recruitment on this inpatient psychiatry unit, only 11 older adults returned to their homes in the community after discharge from the hospital. We are increasingly relying on long-term care facilities as housing for these individuals. The older adults in this study clearly benefited from the sense of independence and community integration that they achieved by moving back home into their communities. Further examination of the supports necessary to facilitate successful community integration is necessary to ensure that older adults are given every opportunity to succeed in their communities.

This study has highlighted the importance of a sense of independence in the community integration process. This concept of independence was quite different from the rugged individualism that comprises the North American ideal of independence. Current literature has begun to examine the concepts of

independence and dependence from the perspective of older adults with chronic physical disabilities (Falter et al., 2003; Gignac & Cott, 1998; Mack et al. 1997). This research needs to continue to listen to the voices of the older adults and to be expanded into the area of mental health.

Literature in the area of mental health and developmental disabilities has shown that independence plays a significant role in both empowerment and recovery (Nelson, Lord, & Ochaka, 2001; Pedlar et al., 1999). This study has provided insight into the link that these three concepts have in the process of community integration. Research with older adults with mental health issues should begin to incorporate the various theories of empowerment, inclusion, independence, recovery, and community integration that exist within the mental health literature in order to gain a better understanding of the meanings and interaction among the four concepts.

Caregiver recruitment was unsuccessful in this study, as described in Section 6.2. Information from these caregivers would be extremely valuable, especially in light of the instrumental support that they provided to the older adults in this study. Future investigations could utilize information from the caregivers in order to better understand the experience of the older adults. As well, research specifically designed to understand the experiences of the caregivers themselves would be helpful and could provide valuable insight into the concept of social support and the role that it plays in community integration for older adults with mental health issues.

As discussed in Section 6.2, all of the older adults in this study had fairly positive experiences with community integration after discharge from the hospital. Future studies should endeavor to hear the stories of those individuals who were not so successful, those who were not coping well in the community and those who had relapsed and been readmitted to the hospital. These perspectives would be invaluable in helping us to understand the experience of community integration for older adults with mental health issues.

6.4 Recommendations for Practice

Better knowledge of community integration will assist practitioners and policy makers in determining what types of services need to be available within the community to increase community tenure. Health care practitioners often tend to focus on addressing tangible, structural issues faced by older adults with mental health issues. In my opinion, we have been too focused on these issues and have not been truly present and listening to the needs of these individuals. Despite physical health challenges and with adequate supports, home is where these individuals have an opportunity to thrive. The feelings of control and independence attained in their own environment can have a strong positive impact on their mental health (Barlow & Williams, 1999). Researchers and practitioners alike need to recognize the vast individual differences among these older adults. We need to specifically tailor our services to meet these diverse needs and incorporate strategies that work for each individual. The stories of the older adults should not only inform program development but they should also shape the outcomes to be measured. Focusing solely on objective measures of

community integration such as recidivism does not adequately capture the experiences of these older adults. Measures need to incorporate subjectivity that enable listening to, and placing value on, the perspectives of the older adults.

A smooth, gradual transition from the hospital back into the community was vital to the well-being of the older adults in this study. Being able to spend short times at home long before actually being discharged from the hospital was extremely helpful to all of the participants. It allowed them to gradually get back into their routine at home and made the final discharge much less intimidating. The link with outpatient supports prior to their discharge from the inpatient unit also contributed to a smooth transition. To facilitate successful community integration, efforts should be made by practitioners to ensure that the transition is a smooth and gradual one and that the supports mentioned above are in place prior to discharging older adults from the hospital.

Practitioners need to be aware of the substantial role that social support plays in the community integration process, especially support from family members. Social support has been positively related to quality of life and enhanced mental health of both individuals with mental health issues (Oliver et al., 1996) and their caregivers (Doornbos, 2002; Pearlin & Skaff, 1995). Individuals who feel supported within the community tend to have more satisfying experiences with community integration (Lee et al., 2001). The older adults in this study all reported that supportive relationships with family members was a key factor that contributed to their success in the community. Older adults should take advantage of this support and not be afraid to ask for

help, despite concern over caregiver burden. Conversely, as practitioners, we need to be aware of the potential for caregiver stress and burden. We need to support caregivers in their efforts to assist their family members as well as in the struggles that they may face throughout the process.

Community resources can be beneficial to older adults as they move back home into the community. Caution should be taken, however, in assuming that all individuals can benefit from the same types of resources. For instance, as illustrated in this study, traditional activity-based leisure activities were not particularly appealing to the participants. Therapeutic Recreationists should take the time to investigate leisure opportunities that promote feelings of self-worth, such as ongoing educational opportunities or volunteering. Productivity and self-worth were strong facilitators of community integration for these older adults. Involvement in activities that promote these feelings can be highly beneficial to older adults with mental health issues.

Independence and community integration appeared to have strong health benefits to the older adults who participated in this study. If we can better address the needs of these individuals in the community, their tenure there would increase. Hospital recidivism would eventually decrease and the quality of life of older adults with mental health issues would subsequently be enhanced.

6.5 Final Words

This study set out to examine the experiences of community integration for older adults with mental health issues. The concepts and theory building that

emerged from this study have contributed to the current knowledge and will be useful in the development of future studies of community integration for older adults with mental health issues. Although leisure was not central to the concepts and understanding that emerged, it did play an important role in promoting feelings of self-worth and, concomitantly, independence. Once we have a better understanding of the process of community integration for older adults with mental health issues, we will be better able to determine whether recreation and leisure practitioners might play a more active role in the community integration process.

This research project has provided me with an opportunity to share in the lived experiences of older adults with mental health issues. This privilege has provided me with new insight into the lives of these older adults and their experience in their communities after leaving the hospital. It is my hope that I have been able to capture the depth of these experiences and that this thesis is reflective of the strength and the passion of these individuals.

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Appendix A

Interview Guide for Clients

Preamble: Hello. I am Shannon Hebblethwaite and I am working with the Therapeutic Recreation Department at Baycrest as a graduate student at the University of Waterloo. Thank you for agreeing to participate in the study. I would like to ask you some questions about your experience when you were discharged from the Psychiatry Unit at Baycrest. I am interested in learning about the process of moving back into the community and how that experience has been for you. If you are uncomfortable with any of the questions, you do not have to answer them. I am going to turn on the tape-recorder now so that I can have an accurate account of our conversation today. Is this okay with you? Do you have any questions before we begin?

1. How long has it been that you have been living back at home after discharge?
2. Can you describe for me what it was like for you when you were discharged from the Psychiatry Unit at Baycrest (4 East)?
3. How would you describe your experiences at home or within your community since then?
4. Would you describe yourself as feeling ready or prepared for the move back into the community? Why or why not?
5. What things do you feel have helped you in this move?
6. What things do you feel have hindered you in this move?
7. Do you have any suggestions for things that could make the move as easy as possible?

Appendix B

Interview Guide for Caregivers

Preamble: Hello. I am Shannon Hebblethwaite and I am working with the Therapeutic Recreation Department at Baycrest as a graduate student at the University of Waterloo. Thank you for agreeing to participate in the study. I would like to ask you some questions about [family member/loved one]'s experience when he/she was discharged from the Psychiatry Unit at Baycrest. I am interested in learning about the process of moving back into the community and how that experience has been for your [family member/loved one]. If you are uncomfortable with any of the questions, you do not have to answer them. I am going to turn on the tape-recorder now so that I can have an accurate account of our conversation today. Is this okay with you? Do you have any questions before we begin?

1. How would you describe [family member/loved one]'s experiences at home or within your community after discharge from the hospital (4 East)?
2. Could you describe for me what it was like for [family member/loved one] was discharged from the Psychiatry Unit at Baycrest (4 East)?
3. Would you describe [family member/loved one] as feeling ready or prepared for his/her move back into the community? Why or why not?
4. What things do you feel have helped [family member/loved one] in this move?
5. What things do you feel have hindered [family member/loved one] in this move?
6. Do you have any suggestions for things that could make the move as easy as possible?

Date:

Dear Participant:

Title of Project: Understanding the Move Back into the Community

Under the supervision of Dr. Alison Pedlar at the University of Waterloo, I am conducting a study of how the move goes back into the community for clients who have been discharged from the Inpatient Psychiatry Unit (4 East) at Baycrest. This study is part of my Masters thesis in the Department of Recreation and Leisure Studies at the University of Waterloo.

I am interested in learning about the experience of moving back home into the community after a brief stay on 4 East. Little is known about the move back home into the community. I want to learn more about this move directly from you, as you are the one with the most knowledge about the experience. I am hopeful that what we learn from this study will help others who are going through similar experiences of moving back into the community.

This letter is an invitation for you to participate in this study. I would like to provide you with more information about this project and what your involvement would be, if you decide to take part.

Participation in this study is entirely voluntary. If you choose not to participate, it will in no way affect the service that you receive at Baycrest. Your participation will be totally confidential. Only I will be aware of your identity. Your name will not be used in any of the reports about the study and I will be the only one who has access to any paperwork with your name on it.

We would not expect any risk or harm for you by being involved in the study. The telling of your experience could, however, prove to be somewhat emotional for you. If you feel that you are experiencing any distress because of the interview, we can arrange for you to speak with your psychiatrist at Baycrest. If I feel that you plan to cause harm to yourself or someone else, it will be necessary for me to contact your psychiatrist at Baycrest.

Your involvement would consist of one interview with myself where you will have the opportunity to share your experience with me. This interview would last approximately 1 – 1 ½ hours and will be audio-taped with your permission. You may choose whether or not you will answer any or all of my interview questions. I will contact you by telephone after the interview to briefly confirm what we have discussed in the interview. As well, with your consent, I would like to contact a person who is close to you, for example, a family member or a friend, who has been involved in your experience of moving back into the community. If you prefer that I not contact anyone who has been involved with your move, I would still invite you to participate in the study. You may withdraw from the study at any time. If you choose to withdraw, this will not affect the services you receive at Baycrest.

If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participation, please contact me, Shannon Hebblethwaite at (519) 503-2436 or my advisor, Dr. Alison Pedlar at (519) 888-4567 ext. 3758.

This project has been reviewed by, and received ethics clearance through Baycrest's Research Ethics and Scientific Review Committee as well as the Office of Research Ethics at the University of Waterloo. If you have any comments or concerns resulting from your participation in this study, you can contact any of the following people:

Breda Chug, Director of Therapeutic Recreation Services (416)785-2500 ext. 2331

The Baycrest Client Representative at (416)785-2500 ext. 2570

Dr. Susan Sykes, University of Waterloo Research Ethics (519)888-4567 ext. 6005

If you are interested in participating in this study, please fill out the attached form and return it in the envelope provided.

Thank you for your interest and involvement. I look forward to speaking with you about your experience of moving back from Baycrest into the community.

Sincerely,

Shannon Hebblethwaite

I would like to participate in this study.

Name of participant (please print): _____

Signature of participant: _____

Telephone number: _____

Appendix D

Client Recruitment Script

Contact by Recreation Therapist, Inpatient Psychiatry Unit

The Therapeutic Recreationist (TR) will meet with the client prior to his/her discharge from the unit. The TR will visit and say that Shannon Hebblethwaite, under the supervision of Dr. Alison Pedlar at the University of Waterloo, is conducting a study on the experience of moving back into the community after leaving the psychiatry unit. We are asking people who are leaving the unit and moving back to their homes in the community if they would be interested in participating.

We hope that this study will help us to identify what helps you in the move back into the community and what might be improved to make this transition easier for you. The researcher is a graduate student from the University of Waterloo, Shannon Hebblethwaite. Your involvement would consist of an interview with Shannon, approximately 1-1 ½ hours in length, to discuss your experience of your move back home. This interview won't take place until approximately 3 months from now in order to give you time to settle at home.

Your participation is completely voluntary and your identity will be kept anonymous. Only Shannon will know the names of the participants. If you choose not to participate, this will in no way affect the services that you now receive or may receive in the future at Baycrest.

If you think you would be interested in participating, I am going to leave you with a letter from Shannon that explains more about the study, along with a reply slip and an envelope addressed to Shannon. You can sign the form and return it to Shannon in the envelope.

Do you have any questions?

Many thanks for your time.

Appendix E

Consent Form for Interview

Title of Project: Understanding the Move Back into the Community

I have read the information letter provided by Shannon Hebblethwaite, graduate student in the Department of Recreation and Leisure Studies at the University of Waterloo. I have received a copy of this letter and have been given an opportunity to ask questions. I understand that I am agreeing to take part in an individual interview to explore my experience of moving back to my home in the community after a brief stay on 4 East. It is my choice whether to answer any or all of the interview questions.

I am also aware of the following:

- The interview will be tape-recorded with your permission. The tapes will only be accessible to the researcher.
- The interview will last approximately one hour.
- Quotes from the interview may be included in the thesis and/or publications that may come from this, with the understanding that the quotes will be anonymous.

My consent is made under the following conditions:

- My participation is totally voluntary and in no way will affect the services I, or my family member, now receive or may receive in the future from Baycrest Centre for Geriatric Care.
- All information is completely confidential and no names of participants will be released.

- I may refuse to answer any questions or withdraw from the study at any time without affecting the services that I receive at Baycrest.

This study has been reviewed by, and received ethics clearance through the Research Ethics and Scientific Review Committee at Baycrest as well as the Office of Research Ethics at the University of Waterloo. I may contact either of these offices if I have any concerns or comments resulting from my involvement in the study.

Consent for Interview:

Participant's name (please print) _____

Participant's signature _____ **Date** _____

Consent for Audiotaping:

Participant's name (please print) _____

Participant's signature _____ **Date** _____

Appendix F

Consent Form for Follow-Up Verification by Telephone
and Permission to Contact Caregiver

Thank you for taking part in the interview today. The information provided will help me to understand the experience of moving back into the community for people with mental health issues. When I analyze the data, I will look for themes or issues arising from each interview and then summarize the findings across groups.

To make sure that I have accurately captured the important issues that emerged from each interview, I would like to contact you within the next couple of weeks. I will conduct a 15 minute follow-up by telephone to: check my findings, see if you agree with major points I felt emerged from the discussion; and to see whether you have any further thoughts to add. As well, if you agree, I would like to contact a person who is close to you, for example, a family member or friend, who has been involved in your experience of moving back into the community. I am interested in understanding the experiences of people who may have been close to you during your move back into the community.

Giving your permission allows us to contact you by phone a few days from now as well as to contact your family member or friend. If you do not wish to participate or participation is inconvenient, no further calls will take place. I will keep these forms secure. I will not give out your name and number to anyone or use it for any purpose outside of this research project. Do you have any questions?

Participant Consent

You have explained the purpose of this follow-up to my satisfaction, and I have had the opportunity to ask questions. By signing below, I give my permission for the researcher to call me at the number below to arrange a 15 minute follow-up by phone. I understand that I may choose not to participate at the time you call me for follow-up purposes. Should I decline, you will make no further contact and will destroy this form.

Participant's name (please print) _____

Phone number _____

Participant's signature _____

Date _____

Most convenient days to call:

Sun__ Mon__ Tues__ Wed__ Thurs__ Fri__ Sat__

Best time to call: morning__ afternoon__ early evening__

Consent to contact family member/loved one

By signing below, I agree that the researcher may contact my family member/friend to arrange an interview. I understand that his/her name and phone number will not be given out to anyone or used for any purpose outside of this research project.

Participant name (please print): _____

Participant signature: _____

Date: _____

Family member/friend's name: _____

Family member/friend's telephone number: _____

Date:

Dear (*Insert Name of Participant*),

I would like to thank you for your participation in this study. As a reminder, the purpose of this study is to understand the experience of moving back into the community after being discharged from the Inpatient Psychiatry Unit at Baycrest. The information collected from our discussion today will contribute to a better understanding of this process of moving back to the community and will hopefully help other people in similar situations as you.

Please remember that any information about you as an individual participant will be kept confidential. Once all the data are collected and analyzed for this project, I plan on sharing this information with the research community through seminars, conferences, journal articles, and policy papers, but none of the study participants will be identified by name. I will be contacting you as we start to analyze the findings so that you may verify that I am correct in my interpretation of things. I shall also provide you with a summary report when the study is finished.

This project has been reviewed by, and received ethics clearance through Baycrest's Research Ethics and Scientific Review Committee as well as the Office of Research Ethics at the University of Waterloo. If you have any comments or concerns resulting from your participation in this study, you can contact any of the following people:

Breda Chug, Director of Therapeutic Recreation Services (416)785-2500 ext.
2331

The Baycrest Client Representative at (416)785-2500 ext. 2570

Dr. Susan Sykes, University of Waterloo Research Ethics (519)888-4567 ext.
6005

Thank you again for your valuable contribution to this study. I am confident that the information gained will be helpful to other people in similar situations as you.

Sincerely,

Shannon Hebblethwaite